Pandemic Influenza: Risk Perception and Protective Behaviours in People with Schizophrenia

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October 2014

A thesis submitted for the degree of

Doctor of Philosophy (Medical Science) at

The Australian National University

I hereby declare that this submission is my own work and that to the best of my knowledge and belief, it contains no material previously published or written by another person, nor material which has been accepted for the award of any other degree or diploma of the university or other institute of higher learning, except where due acknowledgement has been made in the text.

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STATEMENT OF CANDIDATE'S CONTRIBUTION TO RESEARCH

The thesis research project arose out of the candidate's clinical interest in, and commitment to, improving the physical health of people with a mental illness. This focus was generated by him pursuing a career in clinical and academic psychiatry after having worked as a general practitioner in the community for thirteen years.

The candidate conceived the idea of examining risk perception and willingness to adopt protective measures during a pandemic influenza, in people with mental illnesses, with a focus on schizophrenia in this research project. A cross-sectional survey was conducted comparing the responses of 71 adults with schizophrenia, from both inpatient and community settings, with 238 people attending general practices. In addition, a follow-up qualitative study, consisting of eleven in-depth interviews with people with schizophrenia, was carried out. The study designs, recruitment strategies, and methodologies were all developed by the candidate. The statistical analyses and interpretation of results were also carried out by the candidate. A number of items used in the questionnaire had been previously employed, after field-testing, by his principal supervisor, Professor Beverley Raphael, and her colleagues, in pandemic influenza research involving the general population of New South Wales. These have been duly acknowledged in the thesis.

Professor Raphael, the chair of the supervisory panel, provided regular guidance and overall supervision of the study.

Dr Rebecca Reay, a part-time research officer, contributed to the cross-sectional survey by assisting the candidate with formatting, printing, distribution and collection of questionnaires and information brochures and posters involved in the study. Australian National University biostatistician, Dr Bruce Shadbolt, was consulted, and provided expert advice, on study design and statistical methods, for both the cross-sectional survey and the qualitative study. He provided assistance on further occasions with the analysis and interpretation of results of the survey. Associate Professor Jeffrey Looi, Deputy Head of the Academic Unit of Psychiatry and Addiction Medicine at the Australian National University, also provided assistance with data analysis and interpretation.

Dr Jeff Cubis and Professor Gerard Byrne, in their role as supervisory panel members, provided regular feedback on the general progress of the study. Professor Raphael, Associate Professor Looi, Dr Reay, Dr Cubis and Professor Byrne all provided edits, as co-authors, on papers prepared for intended publication.

The candidate independently wrote the first draft of all chapters in this thesis. He revised them based on feedback provided by members of the supervisory panel, Associate Professor Looi, Dr Reay, and Dr Shadbolt. There are some

blocks of text taken from a publication, arising from this research, where the candidate was the first author. He wrote the first draft of this paper and edited it following review by its co-authors.

The ethical principles outlined by the Human Research Ethics Committee of the Australian National University have been adhered to in the preparation of this thesis.

Paul Maguire

ACKNOWLEDGEMENTS

I acknowledge and am very thankful to the participants for taking the time and effort to be involved in the research project. It was inspiring to receive their positive feedback and encouragement about endeavours to improve their physical health.

I gratefully acknowledge the invaluable support, encouragement, expert guidance and time provided by my principal supervisor, Professor Beverley Raphael. Her energy, erudition and wisdom were of enormous value in all stages of this research project. I similarly acknowledge and respect the clarity and depth of feedback provided by my other panel members, Dr Jeff Cubis and Professor Gerard Byrne, the statistical advice and expertise of Dr Bruce Shadbolt, and the statistical and editing advice from Associate Professor Jeffrey Looi. Dr Rebecca Reay has been an excellent and much appreciated source of knowledge, inspiration, encouragement, editing and formatting suggestions, and general practical advice.

In addition, I thank my other colleagues and friends in the Academic Unit of Psychiatry and Addiction Medicine at the Australian National University for their collegial spirit, positive attitudes, good humour and unfailing sense of enquiry and desire to extend the current state of knowledge and understanding of mental illnesses and the challenges faced by those suffering from them.

Finally, I would like to thank my wife Tania, and our two children, Capella and John, for their generous support and encouragement throughout this research project.

THESIS ABSTRACT

Pandemic influenza remains a major public health threat facing the 21st century, heightened by the possible future emergence of a mutant strain of the highly pathogenic avian influenza virus (H5N1). As emphasized by the Australian Health Management Plan for Pandemic Influenza (2009), two core components of an effective response plan are: (1) communication of the best available health information to the public during the pandemic, and (2) minimization of the transmission of the influenza virus. Despite the increased vulnerability of people with schizophrenia in the event of a pandemic influenza, there is a dearth of research examining: (1) how they obtain information on health matters, (2) how they perceive the risks associated with pandemic influenza, and (3) what they are prepared to do about those risks. The research project, consisting of a cross-sectional survey and a qualitative study with in-depth interviews, was designed to examine these issues with the aim of reducing the negative health impact of pandemic influenza on people with schizophrenia.

In the cross-sectional survey, a purposive sample of 309 participants was obtained from health care settings in the Australian Capital Territory (ACT), in Australia. This comprised 71 adults diagnosed with schizophrenia, recruited from public mental health care settings, and 238 adults without schizophrenia, a comparator group, recruited from thirteen urban general practice settings. The patients with schizophrenia, all receiving care from a treating psychiatrist who confirmed their diagnosis, were recruited from a hospital psychiatric inpatient unit, four community mental health centres, and a residential psychiatric rehabilitation unit. Differences in age, gender and socio-economic status

between the two groups were explored and adjusted for in regression analyses. All participants completed a questionnaire examining their use of health information sources, and their perceived risk of, and willingness to adopt protective measures against, the concurrent H1N109 influenza ('swine flu') pandemic. Principal measures used were 5-point Likert scales, and open-ended and binary Yes-No questions. The qualitative study, comprising eleven in-depth interviews with people with schizophrenia, was carried out to further explore how influenza was viewed. The purposive sample was recruited from a community mental health care setting, where these patients were engaged in psychiatric care.

The cross-sectional survey revealed that the most commonly used sources for obtaining at least a moderate amount of information on health matters, for people with schizophrenia, were doctor (59.2%), family and friends (53.5%), and television (52.1%). However, compared with adults attending a general practice, people with schizophrenia were found to be less likely to obtain health information from their doctor (adjusted odds ratio = 0.27, 95% CI = 0.12 - 0.60) and the Internet (adjusted odds ratio = 0.43, 95% CI = 0.22 - 0.88), and less likely to trust their doctor (adjusted odds ratio = 0.22, 95% CI = 0.06 - 0.74) as a source of information on health matters. In the schizophrenia group, 54.9% perceived at least a moderate risk to themselves associated with H1N109; 37.1% perceived a substantive likelihood of contracting H1N109 if no precautionary actions were taken; 63.2% believed it would be serious if they did contract the virus; and close to two thirds believed it was likely they could avoid contracting swine flu. Between-group regression analysis revealed no statistically significant

differences between participants with schizophrenia and people attending a general practice in these risk perception variables. The majority of participants with schizophrenia reported that they would be at least moderately willing to be vaccinated (74.3%), isolate themselves (73.2%), wear a face mask (54.9%) and increase hand washing (88.6%) if advised to by government health authorities. However, compared with adults attending a general practice, people with schizophrenia were less willing to receive a vaccination (adjusted odds ratio = 0.41, 95% CI = 0.19 - 0.88) and less willing to isolate themselves (adjusted odds ratio = 0.41, CI = 0.25 - 0.65). They also perceived vaccination as riskier for an adverse reaction (adjusted odds ratio = 2.17, 95% CI = 1.03 - 4.56), had more concern about 'catching the flu' from vaccination (adjusted odds ratio = 2.19, 95% CI = 1.48 - 3.25), and had less self-efficacy for isolation (adjusted odds ratio = 0.44, 95% CI = 0.29 - 0.66). For people with schizophrenia, the main perceived barriers were: (1) for vaccination - concern about side effects (36.6%), cost (28.2%) and transport to a health facility to receive the vaccination (19.7%); (2) for isolating themselves - loneliness/missing social contact (38.0%), accessing food and groceries (22.5%), and boredom (18.3%); (3) for wearing a face mask - appearance / stigma (32.4%), the discomfort of the mask (16.9%), and difficulty breathing (15.5%); and (4) for increased hand washing - access to facilities to wash (29.8%), concerns about skin irritation (15.1%), and having the time to do it (14.7%).

Thematic analysis of the in-depth interviews in the qualitative study revealed important insights into understanding how people with schizophrenia view influenza including: an identified need for information on symptom profiles

enabling a person to distinguish between a 'cold' and 'flu'; the presence of a large range of 'illness experiences' associated with having influenza; an important role for trust in general practitioners to advise on need for vaccination, and to provide a physical 'checkup'; strong endorsement of vaccination and hand washing as protective measures; a belief in 'alternative medicine' does not preclude engagement with a general practitioner and willingness for vaccination; how to protect against a circulating influenza virus, including whether a vaccination is necessary, was viewed as important information for people to know; public messaging about influenza through posters in public places was viewed as important, with a key role also for television; there were reported low levels of concern and risk perception related to the 2009 swine influenza pandemic and also with respect to a possible future influenza pandemic, including 'bird flu'.

In conclusion, people with schizophrenia attending public mental health care settings appeared to have similar risk perceptions about the 2009 swine influenza pandemic to adults without schizophrenia, attending a primary care setting. They reported being generally willing to adopt protective measures against a pandemic influenza but were less likely to be willing to receive an influenza vaccination and to isolate themselves, compared with people attending a general practice. Hand washing and vaccination were strongly endorsed protective measures, while wearing a face mask was the least favoured. People with schizophrenia were less likely to trust and obtain health information from their doctor, and less likely to access the Internet for health information than people attending a general practice. Despite this, people with schizophrenia viewed their doctor as an important source of health information, with a key role

to play during influenza outbreaks, including providing advice on whether a vaccination is required and conducting a physical examination. Public messaging, information about the characteristic symptoms of a prevailing influenza, and knowledge of how to protect against an influenza outbreak, were seen as important by people with schizophrenia. Further research is required to: (1) inform on the development of strategies to enhance clear, accurate and timely communication of relevant health information during a pandemic, to people with schizophrenia, and (2) promote uptake of effective protective measures, especially hand washing and vaccination, by developing strategies and educative processes aimed at emphasizing benefits, overcoming perceived barriers (including misconceptions about vaccination side-effects) and enhancing self-efficacy. Other vulnerable groups, including people with depressive disorders, may also benefit from these measures.

PUBLICATION ARISING FROM THE THESIS

- **Maguire PA,** Reay RE, Looi JCL, Cubis J, Byrne GJ, Raphael B Neither the internist nor the Internet: use of and trust in health information sources by people with schizophrenia. Australian and New Zealand Journal of Psychiatry 2011 45:489 - 497 (Appendix 1)

ORAL PRESENTATIONS ARISING FROM THE THESIS

- **Maguire PA,** Reay RE, Looi JCL, Cubis J, Byrne GJ, Raphael B Neither the internist nor the Internet: use of and trust in health information sources by people with schizophrenia. Canberra Hospital Annual Research Meeting, The Canberra Hospital Auditorium, Canberra, May 26th 2010

- **Maguire PA**, Reay RE, Looi JCL, Cubis J, Byrne GJ, Raphael B Pandemic influenza: willingness of people with schizophrenia to adopt protective measures. Canberra Health Annual Research Meeting, The Canberra Hospital Auditorium, Canberra, June 6th 2011

- **Maguire PA**, Reay RE, Looi JCL, Cubis J, Byrne GJ, Raphael B Pandemic influenza: willingness of people with schizophrenia to adopt protective measures. Australasian Society of Psychiatric Research (ASPR) Annual Meeting, Dunedin, December 6th 2011 (Appendix 2)

ABBREVIATIONS

ACE: Angiotensin Converting Enzyme

ACQSHC: Australian Commission on Quality and Safety in Health Care

ACT: Australian Capital Territory

AHMPPI: Australian Health Management Plan for Pandemic Influenza

AI: Avian Influenza

AIDS: Acquired Immune Deficiency Syndrome

AOR: Adjusted Odds Ratio

ASPR: Australasian Society for Psychiatric Research

CATI: Computer Assisted Telephone Interview

CATIE: Clinical Trials of Antipsychotic Treatment Effectiveness

CDC: Centres for Disease Control and Prevention

COPD: Chronic Obstructive Pulmonary Disease

ECDC: European Centre for Disease Prevention and Control

Exp(B): Exponential of Regression Coefficient B

FDA: Food and Drug Administration

Flu: Influenza

GP: General Practice

H: Haemaglutinin

HCAI: Health Care Associated Infection

HIV: Human Immunodeficiency Virus

H1N109: Haemaglutinin 1 Neuraminidase 1 2009

H5N1: Haemaglutinin 5 Neuraminidase 1

5HT: 5 Hydoxytryptamine

ICU: Intensive Care Unit

ILI: Influenza-Like Illness

K10: 10-item Kessler Psychological Distress Scale

N: Neuraminidase

NGO: Non-Government Organization

NHHI: National Hand Hygiene Initiative

NSW: New South Wales

OR: Odds Ratio

OTC: Over The Counter

PCR: Polymerase Chain Reaction

RCT: Randomized Controlled Trial

SARS: Severe Acute Respiratory Syndrome

SCZ: Schizophrenia

SD: Standard Deviation

SGA: Second Generation Antipsychotic

SMR: Standardized Mortality Ratio

SPSS: Statistical Package for the Social Sciences

UK: United Kingdom

US: United States (of America)

USA: United States of America

WA: Western Australia

WHO: World Health Organization

CHAPTER ONE

VULNERABILITY OF PEOPLE WITH SCHIZOPHRENIA

DURING A PANDEMIC INFLUENZA

1.1 Introduction

People's *perceptions* of illness and health influence their health *behaviour* (Slovic 2000; Brewer et al. 2007; Petrie et al. 2007). This includes how likely they are to seek professional help for an existing or emerging illness, as well as being involved in activities which may help protect against significant *potential* health threats. People with schizophrenia frequently face major challenges relating to their physical health, in addition to their mental health issues. They are more likely to die from a medical disorder than they are from suicide (Newcomer & Leucht 2011). In the past, people with schizophrenia and other mental illnesses were often incarcerated in asylums, stigmatized and obscured from community awareness, and had little opportunity to understand and initiate protective measures against a range of health threats. Although there are still some profoundly disabled individuals who remain institutionalized, advances in treatment and understanding have enabled most people with schizophrenia to now live in the community, with an expectation of equity in terms of health care and promotion, and social justice in general (Mental Health Consumer Outcomes Task Force 2000). As such, it is important to evaluate which physical illnesses people with schizophrenia living in the community are vulnerable to and why, what they think and feel about those illnesses and the associated risks, and what may be helpful in assisting them

protect against or treat those illnesses. One such important health threat is influenza, and more specifically *pandemic* influenza, which has the capacity to be one of the most significant causes of global mortality in the 21st century.

The internationally accepted definition of a pandemic is an epidemic occurring worldwide, or over a very wide area, crossing international boundaries and usually affecting a large number of people (Last 2001; European Centre for Disease Prevention and Control 2012). The WHO criteria for a pandemic influenza include two key elements (World Health Organization 2009). First is the emergence of a new subtype of influenza virus capable of infecting humans, to which most (if not all) people have not been previously exposed, and therefore, have no or minimal natural immunity against. Second is that this viral strain has the capacity for efficient human-to-human transmission. There has been controversy over whether hypervirulence (i.e. producing a higher case fatality rate than seasonal influenza viruses) of the viral strain should be included as a third criterion. For instance, Collignon (2010) has argued that the term 'pandemic' may evoke unnecessary fear and panic if used when the viral strain is not more virulent than seasonal influenza. He has suggested that the term 'pandemic influenza' is best reserved for an influenza outbreak that not only spreads quickly but is also associated with a hypervirulent viral strain. However, the WHO has never included hypervirulence in its definition of a pandemic influenza, and this is representative of the broader view in the scientific community.

Pandemic influenza continues to pose a major public health threat in the 21st century. In addition to significant mortality and morbidity, it has the capacity to cause major social and economic disruption (Potter 2001). Health outcomes in a pandemic influenza are influenced not only by characteristics of the causative viral strain, such as virulence (i.e. case fatality rate) and capacity for human-to-human transmission (Collignon 2010), but also by the implementation of public health measures to mitigate the negative impact. Modeling has shown that preparedness and response planning, and the execution of that plan, can have a favourable impact on health outcomes (Australian Government, Department of Health and Aging. Australian Health Management Plan for Pandemic Influenza 2009).

There are several key factors that may heighten the *vulnerability* of people with schizophrenia who contract influenza during a pandemic. These include: (1**)** poorer medical outcomes and increased risk of mortality from influenza (and pneumonia), associated with the presence of **comorbid medical illnesses** such as *chronic obstructive pulmonary disease* (COPD), *ischaemic heart disease* (IHD), and *type II diabetes mellitus* (Valdez et al. 1999; Mallia & Johnston 2007; National Health and Medical Research Council 2008; Centres for Disease Control and Prevention 2012), all of which are increased in people with schizophrenia compared with the general population (Jablensky et al. 2011). Although there are no adequate data on overall influenza infection rates in people with schizophrenia compared with the general population, hospitalization rates for influenza in an Australian study were increased for

men with schizophrenia (rate ratio = 1.35), and for both men (rate ratio = 1.23) and women (rate ratio = 1.19) with pneumonia (Lawrence et al. 2001). These rates were even higher (rate ratio = 1.75) in a Danish study. Mortality rates from *influenza/pneumonia* are increased in men (rate ratio = 5.39) and women (rate ratio = 3.40) using mental health services compared with the general population (Lawrence et al. 2001). These data are relevant for people with schizophrenia as there are many psychiatric comorbidities, including depression and anxiety, which occur in people suffering from schizophrenia. There is an increased mortality rate from influenza/pneumonia for men with schizophrenia (rate ratio = 2.5) compared with the general population (Lawrence et al. 2001).

(2) poorer medical outcomes from influenza (and pneumonia), associated with **smoking** (Murin & Bilello 2005), **alcohol misuse** (Zhang et al. 2008; Molina et al. 2011) and **obesity** (Murugan & Sharma 2008), all of which are increased in people with schizophrenia compared with the general population (Jablensky et al. 2011). In addition to increasing the *morbidity* and *mortality* rates from influenza compared with non-smokers (mortality rate ratio = 1.78), the *incidence* rate of influenza in smokers compared with non-smokers is double (Murin & Bilello 2005). These data are relevant for people with schizophrenia given that 65-92% smoke cigarettes (Connolly & Kelly 2005; von Hausswolff-Juhlin et al. 2009; Morgan et al. 2012). Respiratory infections are both more common and more severe in people who either misuse alcohol or who are obese, both of which are over-represented in people with schizophrenia.

(3) poor access to, and utilization of, health care services (Goldman 1999; Brown et al. 2000; Druss et al. 2001; Lambert et al. 2003; Kohn et al. 2004; Nasrallah et al. 2006; Newcomer & Hennekens 2007; Newcomer & Leucht 2011), which may approach or exceed the limits of their capacity during an influenza pandemic. Implicated in reduced utilization of health services are: **general factors** such as shortage of general practitioners and the lack of time and resources for physical/medical examination in community public mental health settings (Thwistlethwaite et al. 2008; Goldman 1999; Lambert et al. 2003); **doctor-related factors,** such as ambivalence of medical clinicians to engage in the care of people with a serious mental illness, and the sometimes minimal involvement in physical health issues by psychiatrists (Goldman 1999; Lambert et al. 2003); and **social impoverishment**. People with schizophrenia are considerably more likely than people in the general population to be homeless, unemployed, and socially isolated, all of which have been shown to be barriers to receiving treatment (Folsom & Jeste 2002; Wewiorski & Fabian 2004). **Trust** (discussed further in chapters two, five and seven) has been shown to be an important factor in the utilization of information sources, including accessing and engaging with health services, and influencing the integrity of the doctor-patient relationship and related health outcomes (Safran et al. 1998; Thom et al. 1999; Hall et al. 2001; O'Malley et al. 2004; Thom et al. 2004; Musa et al. 2009). These risk factors for people with schizophrenia are interconnected with one another, forming **vulnerability pathways** (Figure 1). For instance, lifestyle factors such as smoking, alcohol misuse and

Figure 1 Vulnerability pathways for people with schizophrenia for influenza / pneumonia
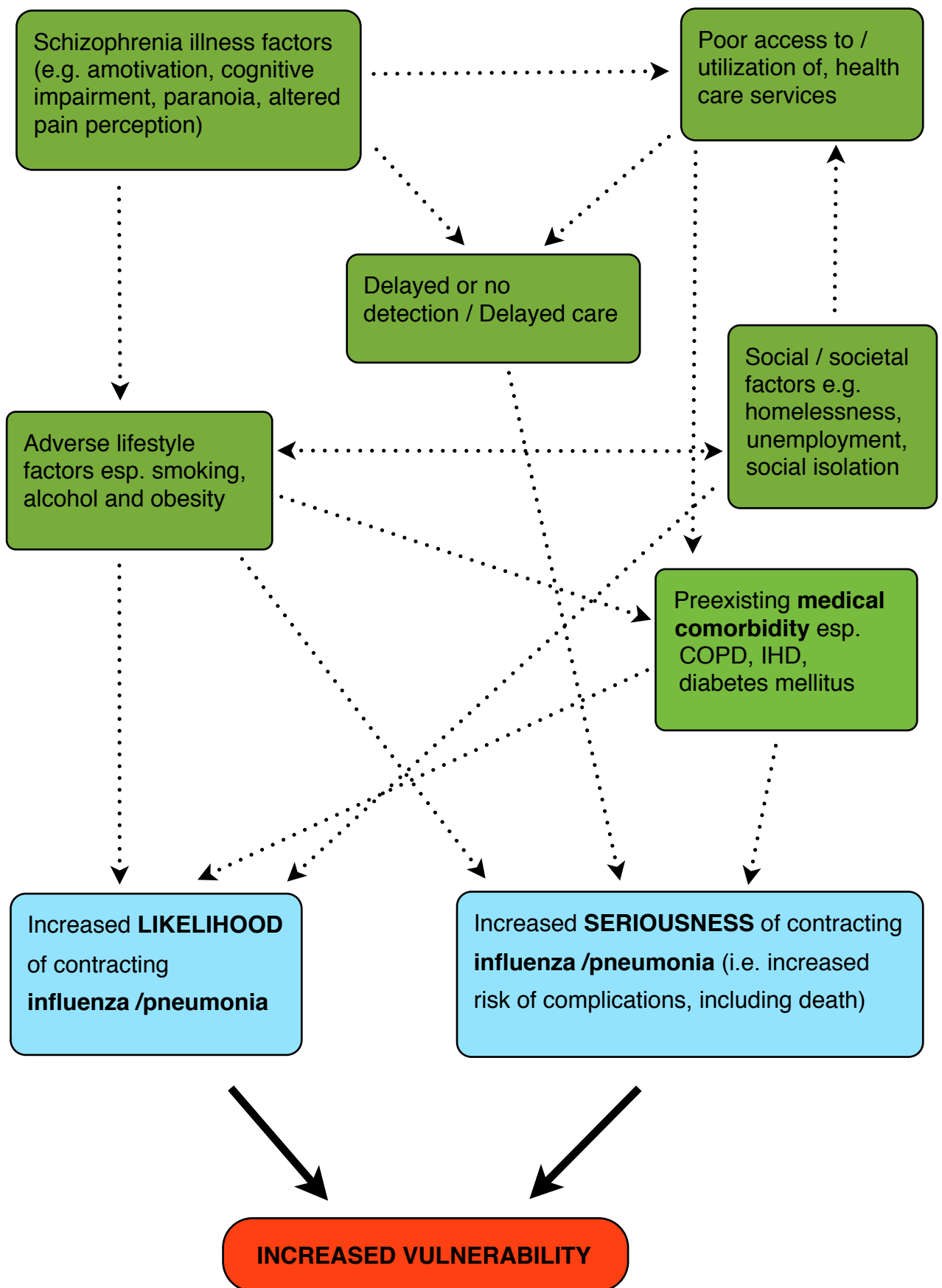
over-eating/under-exercising (leading to obesity) can contribute to medical comorbidity (especially COPD, IHD and diabetes type II), which, in turn, can lead to both an increased likelihood of contracting an influenza/pneumonia infection, as well as increasing the risk of harmful consequences of contracting the infection (by elevating the risk of significant medical complications, including death). Smoking can also induce liver enzymes, leading to increased metabolism of antipsychotic medication, especially olanzapine and clozapine (Sagud et al. 2009). This results in reduced plasma levels of these medications, which may adversely affect treatment outcomes and behaviour (Lambert et al. 2003). Neurocognitive deficits and both the negative (especially amotivation) and positive symptoms (e.g. persecutory delusions) of schizophrenia may lead to reduced contact with a general practitioner or hospital emergency department (Goldman 1999; Lambert et al. 2003), and thereby delay or significantly impede the detection of a significant respiratory infection and provision of appropriate medical care. The negative syndrome of schizophrenia may also increase the likelihood of adverse lifestyle behaviours (Esterberg & Compton 2005), in turn increasing the *likelihood* of contracting influenza, as well as its *extent of harm*. Homelessness and iterancy make it more difficult to receive assertive medical and psychiatric follow-up (Brown et al. 2000; Lambert et al. 2003), which can then lead to increased positive and negative symptoms, and associated risks along the vulnerability pathway mentioned above. Other vulnerability pathways are illustrated in Figure 1. The related notions of *susceptibility* and *sensitivity* are relevant. The vulnerabilities of people with schizophrenia to influenza, especially during a pandemic

outbreak, relate both to their increased susceptibility and increased sensitivity. As shown in Figure 1 above, they have an increased likelihood of contracting a respiratory infection in the first place (increased *susceptibility*), and if they do contract an influenza or pneumonia infection, they are more likely to have a worse outcome (increased *sensitivity*) from this infection due to factors such as delayed care, comorbid medical illness, and smoking, alcohol use, or obesity (as shown in Figure 1). The nature and degree of vulnerability to an influenza pandemic is not fixed and static, but rather will vary over time. For instance, both the number of cigarettes a person is smoking *at the time* of an influenza pandemic as well as the number of *'pack years'* (impacting on the risk of, and extent of, COPD) may influence both the susceptibility and sensitivity dimensions of their vulnerability. The course of an individual's schizophrenia illness over their lifetime may be associated with variations in vulnerability to influenza and pneumonia. In the early stages there may be a period of untreated psychosis, prior to diagnosis and engagement with health services, with increased risk of delayed or absent medical care of an influenza infection (McGorry et al. 2007). Further periods of non-treatment may occur intermittently throughout the course of the illness. Conversely, there may be a period of relative stability during the illness course when an individual with schizophrenia is receiving the appropriate care and treatment, both pharmacological and psychosocial, including social support and assistance with accommodation if required. The nature and quality of social supports, as well as amount of contact with health professionals, will influence vulnerability to both physical and mental health threats.

This chapter explores these vulnerability issues in a literature review.

1.2 Medical comorbidity in schizophrenia

Brief historical context

Observation about the relationship between physical illness and psychosis dates back to antiquity, with Hippocrates noting that fever may sometimes assuage psychotic symptoms. Research supporting a link between mental and physical illness has been published since the early 20th century. In 1912, Bonhoeffer noted an association between psychiatric disorders and poor physical health, with increased mortality compared with the general population. Similarly, Philips, in 1934, reported an increased risk of comorbid physical disorders in people suffering from a mental illness when he reviewed 164 consecutive admissions to an inpatient mental health facility.

Later studies

Subsequently, there have been numerous studies that have supported these early findings. Felker et al. (1996) analyzed data from 20 studies (1949 – 1990) and found that a mean of 50% of psychiatric patients suffered from an already diagnosed medical disorder (Table 1.1). This research also suggested that many patients with severe mental illness have undiagnosed (and therefore untreated) physical conditions. For instance, in a study of psychiatric outpatients (Koranyi 1979), which included people with schizophrenia, 43% were found to have significant medical illnesses, and, of these, almost half (46%) had not been diagnosed by the referring psychiatrist.

Table 1.1 Medical comorbidity in psychiatric patients (adapted from Felker et al. 1996)

Study	Year	Number of patients	Patients with known medical condition (%)
Marshall	1949	175	44
Herridge	1960	209	50
Davis	1965	36	58
Johnson	1968	250	12
Maguire & Granville-Grossman	1968	200	34
Eastwood et al.	1970	100	40
Koranyi	1972	100	49
Forsythe et al.	1977	1110	56
Burke	1978	133	50
Koranyi	1979	2090	43
Hall et al.	1980	100	80
Karasu et al.	1980	200	52
Barnes et al.	1983	144	26
McCorrick et al.	1986	1471	72
Lima & Pai	1987	427	40
Maricle et al.	1987	43	88
Roca et al.	1987	42	93
Walter-Ryan et al.	1987	564	52
Koran et al.	1989	509	52
Bartsch et al.	1990	175	46

Remarkably similar results were found ten years later in a study of patients using Californian public mental health services (Koran et al. 1989), where 45% of patients had physical disease, with 47% of these having been undetected by the treating psychiatrist. The physical diseases identified in these two studies included asthma, chronic obstructive pulmonary disease and tuberculosis but not influenza or pneumonia. However, these findings suggest the possibility that influenza and pneumonia may occur at greater frequency in people with schizophrenia than reported in some population studies.

Although the number of primary studies specifically examining patients with schizophrenia and medical comorbidity has been relatively small, with most of these not controlling for key socio-demographic variables, there have been several reviews. Lipper & Werman (1977) conducted one of the earliest reviews. Their focus was to examine the research literature for evidence to support the claim that intercurrent physical illness in patients with schizophrenia may result in a reduction in their psychotic features. Their findings were negative but they noted significant methodological shortcomings, including: all studies reviewed were retrospective and most lacked a control group; diagnostic criteria for schizophrenia and how improvement in psychotic features was measured were not made explicit; and most of the studies were anecdotal, subjective and qualitative. The authors suggested that there was a need for well-controlled prospective studies to properly examine this research question.

Tsuang et al. (1983) conducted a review based principally on mortality studies. They found that there appeared to a higher incidence of pulmonary disorders in general, gastrointestinal cancer, cardiovascular disease and infectious disease in general, as causes of death in people with schizophrenia, compared with people in the general population, but a lower incidence of lung cancer and rheumatoid arthritis. In addition, there were increased mortality rates from pneumonia in people with schizophrenia compared with the general population.

Harris (1988), in a similar review, also focused on mortality studies. She expressed the view that associations between schizophrenia and a medical illness may give insights into the pathogenesis of both schizophrenia and the given medical disorder. Harris also postulated that negative associations between schizophrenia and some medical disorders might reveal a previously unidentified protective factor existing in people with schizophrenia. She pointed out that even if the morbidity or mortality rate of a given medical disorder is not lower than in the general population, if it is lower than *expected* given increased risk factors, then a protective factor in people with schizophrenia might be in operation. Although acknowledging that, due to methodological shortcomings (e.g. not adjusting for children/lactation), the evidence was inconclusive, she found an increase in the rates of breast cancer in women with schizophrenia, and, like Tsuang et al., a negative association between schizophrenia and both rheumatoid arthritis and lung cancer.

Jeste et al. (1996) examined the issue of physical comorbidity in people with schizophrenia more generally. They identified the contributions of smoking and substance use, as well as psychotropic medication, to physical ill health. Goldman (1999) similarly emphasized the importance of enhanced patient care as an important outcome of research, examining the links between physical illness and schizophrenia. Although he acknowledged that such research might shed light on the aetiology of schizophrenia, he asserted that the principal gain should be improved diagnosis and treatment of comorbid medical disorders occurring in patients with schizophrenia. Goldman reported that nearly 50% of patients with schizophrenia have a comorbid medical condition, but that many of these conditions are either misdiagnosed or undiagnosed. He attributes this increased physical morbidity to high rates of smoking, substance use, obesity and unsafe sexual practices.

Lambert et al. (2003) reviewed common physical conditions that have increased rates in schizophrenia as well as barriers to the recognition and management of these conditions. They also commented on the increased vulnerability to medical comorbidity, especially pulmonary and heart disease, in people with schizophrenia, imposed by life style factors such as smoking, excess alcohol consumption, poor diet and lack of exercise. Although Lambert et al. reported higher rates of respiratory disorders in people with a mental illness compared with the general population, they did not identify which specific respiratory disorders are increased in people with schizophrenia. They comment that men with a mental illness (including men with schizophrenia)

have reduced rates of lung cancer compared with men in the general population. This is a surprising finding given that as a group people with schizophrenia are significantly more likely to be cigarette smokers. Lambert et al., Jeste et al., and Goldman, all identify barriers to accessing and utilizing health care services by people with schizophrenia, both patient / illness factors as well as doctor / health care system factors. These will be discussed later in this chapter (section 1.6).

Chwastiak et al. (2006) found that in a sample of 1,424 participants with schizophrenia in the United States (enrolled in an antipsychotic medication trial), 58% had at least one comorbid medical disorder, including 20% with hypertension and 11 % with diabetes mellitus. Four or more medical conditions were present in 9% of the sample. More severe comorbidity was found in a study of 80 patients in the United States with schizophrenia or schizo-affective, disorder and comorbid alcohol use disorder, who entered a trial of naltrexone treatment (Batki et al. 2009). In this sample, 83% had at least one chronic medical disorder, with hypertension being the most common (occurring in 43% of participants). Carney et al. (2006) conducted a population-based controlled study of people with schizophrenia or schizo-affective disorder (n = 1,074), also in the United States. They found that 71% of participants with schizophrenia/schizo-affective disorder had at least one medical or alcohol/substance use comorbidity (compared with 45.3% of controls). Three or more comorbidities were present in 33% of people with schizophrenia/schizo-affective disorder compared with only 12% in the control

group. A limitation of this study is that the results are presented in such a way that it is not possible to calculate medical comorbidity rates in those who do not have an alcohol/substance use disorder. In fact, the authors use the term 'medical comorbidities' to include both medical disorders and alcohol/substance use disorders.

An Australian national survey of psychosis, conducted in 2010, found high rates of physical comorbidity in people with psychosis (Morgan et al. 2012). Approximately 1.5 million people aged 18-64 years were surveyed, with 63% of those with psychotic disorders meeting the International Classification of Diseases 10th Revision (ICD-10) criteria for schizophrenia or schizoaffective disorder. Other than cancer, rates were increased for all medical conditions (for which there were available comparison data) compared with people in the general population (aged 18-64): 54.8% met diagnostic criteria for metabolic syndrome or were already on treatment, including *at risk levels* for abdominal obesity (82.1%), high-density lipoproteins (49.7%), blood pressure (48.8%), triglycerides (48.0%) and plasma glucose (28.6%); 26.8% reported heart or circulatory conditions; 20.5% had diabetes mellitus; 30.1% had asthma; 11.2% had hepatitis; 7.3% had epilepsy; 24.0% were at high risk for a negative cardiovascular event in the next 5 years based on the Framingham risk equation (Anderson et al. 1990; National Vascular Disease Prevention Alliance 2009). Nutrition was found to be poor: 71.1% reported not eating fruit at all or eating one or less serving a day, and 48.6% disclosed they that did not eat vegetables at all or ate one or less serving per day.

A recent review has been conducted by Jablensky et al. (2011). Their analysis of studies of people with schizophrenia concluded that between 46% and 80% of inpatients, and between 20% and 43% of patients being treated in the community, suffer from a concurrent medical disorder. Jablensky et al. identified evidence for increased rates of the following conditions in people with schizophrenia: chronic obstructive pulmonary disease; ischaemic heart disease; type II diabetes mellitus; infection in general, but especially tuberculosis and HIV; acquired hypothyroidism; irritable bowel syndrome; middle ear disease; and some rare genetic and idiopathic disorders such as intermittent porphyria. They have emphasized, like Jeste et al., that the burden of medical comorbidity may be underestimated, because a diagnosis of a mental illness is often an exclusion criterion in research studies. This review also highlights the important finding of a significant over-representation of metabolic syndrome in sufferers of schizophrenia, with a 4-fold increase risk shown in a Finnish cohort study, and rates as high as 36-51% in a number of key studies (McEvoy et al. 2005; De Hert et al. 2006; John et al. 2009).

Record linkage studies

Two comprehensive record linkage studies have been useful in exploring medical comorbidity in schizophrenia. In first of these, Baldwin (1987) used data from the Oxford Record Linkage Study, which linked together hospitalization, birth and death records over an 8-year period (1963-1970) covering a population of approximately 800,000 in Oxfordshire and Berkshire in the United Kingdom. Out of a total of 367,000 patients, 2,314 were

diagnosed with schizophrenia. Hospitalization rates for people with schizophrenia were compared with rates in the general population. Results are shown in Table 1.2. Although there were no data for influenza, hospitalization for pneumonia in people with schizophrenia was 1.63 times more likely than in the general population. Limitations of this study included the relatively small number of people with schizophrenia, the short follow-up period (mean length of follow-up was 3.25 years) resulting in low statistical power, and that there was no adjustment for socio-economic status (other than age). The second linkage study was carried out by Lawrence et al. (2001) in Western Australia (WA). It linked together hospital admission records, cancer registrations and death records for all users (n = 231,311) of public mental health services in WA between 1980 and 1998. Hospitalization rates, cancer incidence rates and mortality rates were compared with rates in the general population of WA. Results (Table 1.3) are similar to the Oxford study, and are also not adjusted for socio-economic status. Hospitalization rates for influenza were higher for men with schizophrenia but lower for women with schizophrenia, compared with the general population.

Influenza and pneumonia

Other than the record linkage studies mentioned above no studies were identified (at the time of writing) which specifically reported on influenza in people with schizophrenia. Even the literature pertaining to pneumonia (and other specific diagnostic categories of respiratory infection) in people with

Table 1.2 Oxford Record Linkage Study: Hospitalization rate ratios in people with schizophrenia compared with the general population (adapted from Baldwin 1987)

Disease	Hospitalization Rate Ratio
Breast cancer	0.96
Colo-rectal cancer	0.77
Lung / bronchial cancer	0.64
Haematopoietic malignancy	0.33
Oesophageal cancer	2.93
Pancreatic cancer	1.65
Stomach cancer	1.73
Diabetes mellitus	0.47
Parkinson's Disease	2.57
Arteriosclerotic heart disease	1.71
Hypertensive heart disease	0.29
Arteriosclerosis	1.46
Vascular lesions of the CNS	1.26
Pneumonia	1.63
Bronchitis	1.05

Table 1.3 Western Australia Record Linkage Study: Hospitalization rate ratios in people with schizophrenia compared with the general population (adapted from Lawrence et al. 2001)

Disease	Hospitalization Rate Ratios (95% CI)	
	Male	Female
Tuberculosis	3.04 (1.54-6.01)	2.26 (0.84-6.12)
Viral hepatitis	3.58 (2.54-5.05)	4.93 (2.95-8.23)
Female breast cancer		0.97 (0.78-1.22)
Prostate cancer	0.63 (0.39-1.01)	
Lung cancer	1.29 (1.06-1.57)	1.17 (0.84-1.63)
Colorectal cancer	0.52 (0.23-1.16)	1.02 (0.77-1.36)
Malignant melanoma	0.76 (0.42-1.38)	0.93 (0.50-1.71)
Cancer of the cervix		1.64 (1.05-2.54)
Stroke	0.82 (0.64-1.05)	0.86 (0.67-1.12)
Ischaemic heart disease	0.59 (0.49-0.71)	0.60 (0.47-0.76)
Pneumonia	1.23 (1.02-1.47)	1.19 (0.91-1.56)
Influenza	1.35 (0.802.29)	0.27 (0.12-0.60)
Chronic obstructive pulmonary disease	1.12 (0.89-1.46)	1.12 (0.81-1.55)
Asthma	0.49 (0.36-0.67)	0.93 (0.67-1.29)

schizophrenia is sparse. Chen et al. (2010) carried out the only study to have examined the medical outcomes of people with schizophrenia admitted to hospital for pneumonia. The sampling frame was 81,599 adults (aged 18-65) admitted to hospital in Taiwan with a principal diagnosis of pneumonia between 2002 and 2004 (inclusive). Those with a diagnosis of schizophrenia (n = 949) were compared with a matched random selection (n = 2847) of the remainder of the sample frame. Even after adjusting for potential confounders including socio-demographic variables, treating physician, hospital (causing possible clustering effects), patients with schizophrenia were more likely to: (1) require intensive care unit admission (adjusted odds ratio (AOR) = 1.18, 95% CI = 1.37 - 2.40); (2) develop acute respiratory failure (AOR = 1.37, 95% CI = 1.08 - 1.88); or (3) need mechanical ventilation (AOR = 1.34. 95% CI = 1.04 - 1.92). A weakness of this study was that the subtype of pneumonia (e.g. viral vs bacterial) was not identified. In addition, it did not control for smoking.

Monk-Jorgensen et al. (2000) calculated the hospitalization rate ratios (RR) for people with schizophrenia (n = 20,000) admitted to hospital for respiratory disease, compared with matched controls (n = 200,000), in Denmark between 1978 and 1993. Although there was not a specific category for influenza, there were several diagnostic categories for pneumonia (Table 1.4), and the RRs were increased in all of these for patients with schizophrenia. Although the data do not specify whether these pneumonias were primary or secondary it is likely some were secondary to viral respiratory infections, including influenza.

Table 1.4 Danish hospitalization rate ratios for respiratory disease in people with schizophrenia (adapted from Munk-Jorgensen et al. 2000)

Diagnosis (ICD-8)	Hospitalization Rate Ratio	95% CI
Acute pneumonia	2.53	1.55-3.91
Pyothorax	2.40	1.63-3.39
Acute pulmonary oedema	1.91	1.47-2.44
Lung abscess	1.80	1.05-2.88
Lobar pneumonia	1.75	1.39-2.18
Bronchopneumonia, unspecified	1.74	1.56-1.94
Pneumonia, unspecified	1.69	1.55-1.84
Pulmonary collapse	1.67	1.05-2.53
Pulmonary Tuberculosis	1.65	1.14-2.30
Bacterial pneumonia	1.60	1.17-2.13
Acute bronchitis	1.37	1.13-1.66

In summary

Medical comorbidity, including chronic obstructive pulmonary disease, diabetes mellitus, and ischaemic heart disease, is associated with increased vulnerability during a pandemic influenza. There is strong evidence for increased prevalence of these disorders in people with schizophrenia and they are frequently undiagnosed and, therefore, untreated. However, there is also evidence of a possible negative association between schizophrenia and some medical disorders, such as lung cancer. Infection in general, including

pneumonia, is increased in people with schizophrenia compared with the general population, and there are increased hospitalization rates for pneumonia in both men and women with schizophrenia. Hospitalization rates for influenza appear to be increased in men with schizophrenia but decreased in women with schizophrenia compared with the general population. However, under-diagnosis and poor access to health care may result in underestimates in these rates.

1.3 Mortality rates in schizophrenia

Although the earliest commentary on mortality of people with mental illnesses dates back to Graunt in the mid-1600s, the first statistical evidence of increased mortality in people suffering from a mental illness is attributed to William Farr in 1841 (Singer 2001). He reported a 3-14 fold excess of deaths among residents of asylums in England and Wales, compared with the general population. The quality of research into mortality rates in people with mental illnesses, including those with schizophrenia, has improved significantly over the last two decades compared with earlier studies. Samples are larger and better defined, and there is better access to quality comparison data in the general population, allowing calculation of standardized mortality ratios (SMRs). SMRs have become available for all-cause mortality as well as mortality for specific categories such as cancer, infectious diseases and cardiovascular disease, facilitating attempts at prevention, early diagnosis and better management of comorbid medical disorder in people with schizophrenia.

A landmark study was conducted by Brown et al. (2000), in which a 13-year follow-up of 370 patients with schizophrenia revealed a striking 3-fold increase in all-cause mortality rate compared with the general population. Natural causes (i.e. recognized medical conditions) accounted for approximately 63% of the excess deaths in people with schizophrenia. Although the SMR for 'unnatural deaths' (deaths from accidents, suicide and 'undetermined') was particularly high (12.7), unnatural death accounted for only 37% of excess deaths. Death from recognized medical disorders in general was 2.3 times more likely than in the general population. The SMR for the category 'respiratory diseases' (which is likely to have included influenza and/or pneumonia) was 3.17.

There have been three systematic reviews over the past 15 years and all have clearly shown an increased mortality rate in people with schizophrenia. The first, performed by Brown (1997), examined 18 studies published between 1969 and 1996. The studies included in the meta-analysis were restricted to those with samples sizes of more than 100, that had been peer-reviewed, and which were in either English or French language. Additional inclusion criteria were a follow-up period of at least two years, clear data on numbers of observed and expected deaths (so that SMRs could be calculated), and a reported loss of follow-up of less than 15%. The cohorts were drawn from North America, Israel, The Netherlands, Scandinavia and the United Kingdom (as studies from other regions did not meet the inclusion criteria). Eighty percent of people with schizophrenia were found to have died from natural

causes compared to approximately 97% of the general population. Recognized medical conditions accounted for about 59% of the excess mortality with an aggregate SMR of 1.34. There were no specific data on influenza / pneumonia. Of the unnatural causes of death, suicide accounted for 28% of excess deaths, with a SMR of 8.38. Accidental death accounted for about 12% of excess deaths with an SMR of 2.16, and homicide had an SMR of 7.33 but accounted for only about 1% of excess deaths.

The second review, which is widely quoted in the literature, was conducted by Harris & Barraclough (1998). It examined studies published between 1966 and 1995 and included a wide range of psychiatric disorders. The review was restricted to English language peer-reviewed papers with at least two years follow-up, a stated loss at follow-up of less than 10% and adequate data to calculate all-cause mortality, natural-cause mortality and unnatural-cause mortality, and corresponding SMRs. There were 20 studies pertaining to schizophrenia, reporting on a population of almost 36,000 from nine countries, between 1973 and 1995. The all-cause mortality rate was 1.57 times that of the general population. Similar to Brown's findings, about 62% of the excess mortality was accounted for by recognized medical disorders. The largest number of excess deaths in people with schizophrenia compared with the general population was from infectious, respiratory and digestive disorders (but there were no specific data on influenza or pneumonia).

The most recent systematic review, carried out by Saha et al. (2007), examined 37 papers from 25 countries, reporting deaths in people with schizophrenia that were published (or available) between 1980 and 2006. Inclusion criteria were: age of patients ≥ 15 years; availability of primary data on all-cause and/or cause-specific mortality; and reported SMRs or data available on observed and expected deaths from which SMR can be calculated. Findings included a median SMR for all-cause mortality of 2.58. The median SMRs for all-natural causes of death, and for all-unnatural causes of death, were 2.41 and 12.73 respectively. With the exception of cerebrovascular disease, all the major medical causes of death categories had elevated SMRs. For respiratory disease, the SMR was 3.19 and for infectious diseases in general 4.29 (with no specific data on influenza or pneumonia reported). Although Brown in the first meta-analysis found a small but statistically significant male excess in overall mortality, no gender differences were noted in the other reviews.

Despite advances in diagnosis and treatment of many medical disorders and, in many countries, a greater focus on mental illnesses in recent times, the gap between all cause mortality rates in the general population and in people with schizophrenia has not narrowed. On the contrary, there is some evidence that it has worsened (Brown 1997; Osby et al. 2000). This may in part relate to the advent of second-generation antipsychotics (discussed later in this chapter), which have been shown to be associated with an increased risk of obesity, diabetes mellitus and sudden cardiac death (Stahl et al. 2009).

Finally, the Western Australia linkage study described earlier (Lawrence et al. 2001), also reported on mortality rate ratios with respect to specific disorders, including a category for *pneumonia and influenza (*Table 1.5). Mortality rates were calculated in the cohort of patients using mental health services, and

Table 1.5 Mortality rate ratios in patients using mental health services in Western Australia, 1980-98 (adapted from Lawrence et al. 2001)

Cause of death	All mental health services patients		Patients with schizophrenia	
	Males RR (95% CI)	Females RR (95% CI)	Males RR (95% CI)	Females RR (95% CI)
Malignant neoplasms	1.53 (1.46-1.62)	1.32 (1.25-1.40)	0.23 (0.10-0.53)	1.36 (0.89-2.06)
Diabetes mellitus	3.14 (2.71-3.65)	2.47 (2.15-2.84)	< 4 deaths	< 4 deaths
Acute myocardial infarction	1.74 (1.64-1.85)	1.73 (1.63-1.84)	1.42 (0.83-2.42)	0.61 (0.27-1.38)
Other ischaemic heart disease	2.22 (2.06-2.39)	2.21 (2.05-2.38)	2.45 (1.40-4.29)	1.31 (0.62-2.77)
Cerebrovascular disease	3.88 (3.64-4.14)	2.92 (2.17-2.48)	1.30 (0.53-3.21)	1.24 (0.66-2.33)
Other circulatory system	2.70 (2.50-2.91)	2.32 (2.17-2.48)	1.89 (0.87-4.10)	1.70 (0.93-3.10)
Pneumonia and influenza	5.39 (4.84-6.00)	3.40 (3.03-3.82)	2.50 (0.75-8.29)	< 4 deaths
Chronic obstructive pulmonary disease	2.78 (2.55-3.02)	2.37 (2.12-2.66)	< 4 deaths	1.54 (0.56-4.24)

compared with the mortality rate in the general population of WA (i.e. mortality rate ratios). Men utilizing mental health services had 5.4, and women 3.4, times higher mortality rates from the category *influenza and pneumonia* compared with the general population. This was easily the highest mortality rate ratio of any medical cause of death. For schizophrenia specifically, there was a 2.5 times higher mortality rate for men for *influenza and pneumonia,* but less than four deaths for women in this study.

In summary

There is strong evidence that people with schizophrenia have 2-3 times higher mortality rates than people in the general population. Although elevated suicide mortality rate ratios account for some of the excess deaths, most excess deaths (approximately two thirds) are associated with recognized medical disorders, especially cardiovascular and respiratory disease. Influenza and pneumonia were over-represented in males with schizophrenia compared with the general population, suggesting vulnerability during a pandemic.

1.4 Lifestyle factors potentially contributing to vulnerability during a pandemic influenza

Lifestyle factors may influence the vulnerability of people with schizophrenia during a pandemic influenza in two principal ways. First, cigarette smoking, alcohol misuse, and obesity, which are increased in people with schizophrenia compared with the general population, all increase the risk of adverse medical

outcomes in influenza and pneumonia (evidence discussed below). Second, lifestyle factors contribute to the development of medical disorders such as chronic obstructive pulmonary disease, ischaemic heart disease, and diabetes mellitus type II, which are also predictors of poorer medical outcomes in influenza and pneumonia (Centres for Disease Control and Prevention 2012). Lifestyle factors / health behaviours are not fixed entities but rather may change over time (in either direction), may be interdependent with one another, and may have associations with socio-economic status (discussed in detail in Chapter 7). These temporal dynamics may comprise fluctuations over time in: illness severity; engagement with health services; exposure to educative processes; amount and quality of social support; personal and health system finances; advances in medical science; and societal issues such as degrees of marginalization and stigmatization of people with a mental illness.

Smoking

Cigarette smoking has been found to be the greatest contributor to preventable death in the western world (United States Department of Health and Human Services 1989). In a review paper, Murin & Bilello (2005) examined the association between cigarette smoking and 'respiratory tract infections' in the general population. They found that in addition to increasing the risk of developing chronic obstructive pulmonary disease and lung cancer, smoking increases the *incidence* rates of influenza and pneumonia, as well as increasing *morbidity and mortality* from these infections. Identified mechanisms

for these links between smoking and pulmonary infections, were found to operate at multiple levels, and included:

(1) damage to muco-ciliary function with consequent impaired clearance of inhaled particles

(2) promotion of pathogen adherence to the epithelial cells of airways

(3) increased permeability of vascular and epithelial membranes in the alveoli

(4) increased pulmonary inflammatory cells

(5) reversibly depressed natural killer cell function

In the review by Murin & Bilello, smokers were found to have approximately *double* the rate of influenza compared with non-smokers; their influenza infections tended to be more severe than those of non-smokers; and death rates were higher from influenza than they were for non-smokers. For instance, in a sixteen year follow-up study by Rogot & Murray (1980), mortality rates from influenza were 1.78 times higher than in non-smokers. Finklea et al. (1971) measured the influenza antibody titres in college students during an influenza epidemic and found that smokers had higher rates of both clinical and sub-clinical infection. Similarly, the review found cigarette smoking to be strongly associated with pneumonia risk. Lipsky et al. (1986) demonstrated that cigarette smoking increased the likelihood four-fold of developing pneumococcal pneumonia (culture-proven) in a retrospective case control study. However, a methodological shortcoming of this study was that it failed to control for the presence or absence of COPD. In a case control study of the general population, Almirall et al. (1999) demonstrated a positive correlation between the number of cigarettes people smoked and the level of risk of

developing pneumonia. People who had ever smoked had double the risk of contracting pneumonia compared with non-smokers, and approximately one third of community-acquired pneumonia infections were attributable to smoking. Farr et al. (2000) found that a lifetime history of smoking was an independent risk factor for community-acquired pneumonia requiring admission to hospital, even after adjusting for COPD.

The prevalence of cigarette smoking is 2.5-3.0 times higher in people with schizophrenia than in the general population, with 65-92% of people with schizophrenia being smokers (Connolly & Kelly 2005; Levander et al. 2007; von Hausswolff-Juhlin et al. 2009; Morgan et al. 2012). As well as being more likely to smoke, people with schizophrenia tend to smoke more heavily than people in the general population and have higher nicotine levels in the bloodstream, which, in turn, increases the likelihood of dependence (Connolly & Kelly 2005). Deeper inhalation and variation in the structure of nicotine receptors may contribute to this (Freedman et al. 1994; Olincy et al. 1997). Reasons identified by people with schizophrenia for smoking include: boredom; a means of reducing stress and anxiety levels; coping with the 'negative symptoms' and medication side effects; and because their friends smoke (Forchuk et al. 2002; Esterberg & Compton 2005). In addition, there is evidence that nicotine improves mood and cognition by elevating levels of synaptic dopamine in the limbic and prefrontal regions of the brain (Keltner & Grant 2006). Finally, smoking has been shown to induce P450 enzymes in the liver, thereby increasing the rate of biotransformation, with consequent

reduction of serum levels of antipsychotic medications used in the treatment of schizophrenia, and increased risk of relapse (Lambert et al. 2003; Sagud et al. 2009).

Alcohol misuse

Zhang et al. (2008) reviewed the literature relating to the association between alcohol abuse and pulmonary infections. They concluded that pulmonary infections, especially pneumonia, are more common and more severe in people who 'abuse' alcohol, and that these infections are characterized by frequent complications and poor outcomes. Schmidt & de Lint (1972) examined 6,478 patients with alcohol misuse over a 14-year period and found that the mortality rates were 3-fold greater for men, and 7-fold greater for women, compared with the general population. In a case control study of 100 patients with community-acquired pneumonia (Fernandez-Sola et al. 1995), alcohol misuse was associated with greater symptom severity, increased length of hospital stay, longer duration of intravenous antibiotic administration and worse survival rates. In a large cohort study (n = 23,198) of patients requiring hospitalization for pneumonia (Saitz et al. 1997), an additional diagnosis of an alcohol use disorder was associated with longer hospital stays and more frequent need for intensive care unit involvement. In a one-year prospective study of nosocomial pneumonia in general medical and surgical patients, alcohol misuse was found to be a powerful predictors of a fatal outcome (Everts et al. 2000). In their review paper, Zhang et al. (2008) identified several factors contributing to the development of pulmonary

infections in people who misuse alcohol including: dysfunction of protective barriers in the respiratory tract; aspiration; nutritional deficiencies; liver disease; and impairment of host defense mechanisms. The authors found evidence that these factors render treatment of pulmonary infections in patients who misuse alcohol more difficult and that there may be a role for immunomodulatory agents in combination with antibiotics.

Alcohol misuse may occur comorbidly with illicit substance use. Although older studies (Hind 1990) have reported increased rates of community-acquired pneumonia in intravenous drug users compared with the general population, there is a paucity of methodologically robust research on the effects of illicit substance use on respiratory health (Story 2013). The key reasons for this are: logistic difficulties in performing long-term studies on the effects of illegal drugs, and; significant confounding from comorbid cigarette smoking, alcohol misuse and polysubstance use. Putative mechanisms for respiratory sepsis from illicit substance injection include: (1) the stupor induced by some drugs may increase the risk of aspiration, resulting in pneumonia or lung abscess, (2) bacteraemia or septic embolism associated with injection, and (3) impaired immune response (Karpel 2013).

Alcohol and/or illicit substance use disorder is very prevalent in people with schizophrenia, and is the commonest comorbidity (Cantor-Graae et al. 2001; Chen & Murray 2004; Larsen et al. 2006; Gregg et al. 2007). Excluding tobacco, the most frequently misused substances are alcohol and cannabis

(Margolese et al. 2004). In a large prevalence study in the USA (Regier et al. 1990) approximately 34% of people with schizophrenia also had an alcohol use disorder (AUD) (i.e. alcohol abuse or dependence), which was three times more prevalent than in the general population. More recently, Koskinen et al. (2009) conducted a systematic review and meta-analysis of the prevalence of AUDs in the people with schizophrenia. They examined 60 studies published between 1996-2008 (inclusive) and found that the median of AUD point prevalence was 9.4% and the median for lifetime AUD prevalence was 20.6%. They concluded that there might be a descending trend in AUD prevalence in people with schizophrenia with approximately one in every five persons with schizophrenia having a lifetime AUD diagnosis. There was only one study (McCreadie, Scottish Comorbidity Study Group 2003) out of the sixty the authors examined that included a control group to make a comparison with the general population. It found that AUDs were more common in people with schizophrenia, especially alcohol dependence, which was close to two and a half times more prevalent (both point and lifetime prevalence) compared with the general population. In the 2010 Australian national survey of psychosis (Morgan et al. 2012), 50.5% of participants aged 18-64 (58.3% for males, 38.9% for females) had a lifetime history of alcohol abuse or dependence compared with 24.7% of people (35.3% for males, 14.1% for females) in the general population. A similar proportion (54.5%) of people with psychosis aged 18-64 had a lifetime prevalence of illicit substance abuse or dependence (63.2% for males, 41.7% for females) compared with 8.9% in the general population (12.0% for males, 5.8% for females).

Obesity

Obesity has been found to be a risk factor for both the development of respiratory infection as well as for poor outcomes from influenza and pneumonia (Murugan & Sharma 2008; Morgan et al. 2010). Obesity adversely affects respiratory function through its effects on gas exchange, airways resistance, respiratory mechanics, work of breathing, and lung volumes (Murugan & Sharma 2008). The swine influenza pandemic of 2009 impacted particularly severely on people who were obese. There is evidence supporting a disproportionate representation of obesity (Body Mass Index $\geq$ 30 kg/m^2) and morbid obesity (Body Mass Index $\geq$ 40kg/m^2) among hospitalizations, intensive care admissions and deaths from swine influenza in the 2009 pandemic (Morgan et al. 2010).

Numerous studies have shown increased rates (up to twice the prevalence) of obesity in people with schizophrenia compared with the general population (McCreadie et al. 2003; Cohn et al. 2004; Cormac et al. 2005; Allison et al. 2009). In a UK study of hospital inpatients, predominantly with schizophrenia, Cormac et al. found a rate of obesity of 36% in men and 75% in women compared with 17% and 22% respectively in the general population at the time of the study. McCreadie et al. (2003) revealed that 86% of female, and 70% of male, community patients with schizophrenia were either overweight or obese. In the 2010 Australian national survey of psychosis (Morgan et al. 2012), 45.1% of people aged 18-64 with psychosis were obese compared with 21.0% in the general population. As discussed earlier, there is an increased mortality rate from obesity-related medical disorders such as ischaemic heart disease,

in people with schizophrenia compared with the general population. Obesity in people with schizophrenia appears to arise from both increased oral energy intake as well as reduced energy expenditure. There is evidence that people with schizophrenia consume a diet higher in fat (and lower in fibre) and exercise less, compared with adults in the general population (Brown et al.1999; Leas & McCabe 2007). A significant contributor to increased oral energy intake is the appetite-stimulating effect of psychotropic medication (discussed in the next section, 1.5, of this chapter).

In summary

There is strong evidence for the contribution of lifestyle factors to the increased rates of comorbid medical disorders, and poor clinical outcomes in influenza and pneumonia, for people with schizophrenia. Key lifestyle factors increasing these risks are smoking, alcohol misuse, and obesity (resulting from under-exercising and over-eating / poor food choices).

1.5 Effects of psychotropic medication on vulnerability during a pandemic influenza

Although lifestyle and genetic factors are implicated, iatrogenesis is also an important contributor to medical comorbidity in schizophrenia. There is mounting evidence that exposure to psychotropic medication, especially antipsychotics, is associated with an increased risk for obesity, type 2 diabetes mellitus, hypertension, dyslipidaemia and sudden cardiac death (Stahl et al.

2009). Although all these conditions are important, the focus in this section is on medication-related obesity and diabetes mellitus, because these conditions are associated with poorer medical outcomes in influenza and pneumonia, increasing vulnerability during an influenza pandemic.

Weight gain is a well-documented side effect of both first generation (FGAs) and second generation antipsychotics (SGAs) (Marder et al. 2004). However, several randomized trials have provided strong evidence that there is a differential gradient in the propensity to induce weight gain among the available agents, with the dibenzodiazepines (i.e. clozapine and olanzapine) being associated with the most weight gain, and aripiprazole and ziprasidone with the least (Allison & Casey 2001; Lehman et al. 2004; Marder et al. 2004; Casey 2005). Twenty per cent of patients receiving either clozapine or olanzapine gain weight of at least 10% of their pretreatment body weight when treated for at least 10 weeks (Balf et al. 2008). Antipsychotic medications appear to promote weight gain principally by increased ingestion of food, secondary to disruption of appetite / satiety control. Putative mechanisms for this include histamine (H)1 receptor blockade, 5-hydroxytryptamine (5HT) 2c antagonism, hyperprolactinaemia and increased serum leptin, followed by leptin desensitization, causing appetite stimulation (Herran et al. 2001; McIntyre et al. 2001; Monteleone et al. 2002). In addition to the contribution from increased oral intake, there is some evidence for medication-related weight gain being secondary to reduced caloric expenditure (Virkkunen 2002). Genetic factors may also influence the propensity for a given individual

exposed to antipsychotic medication to gain weight (Basile et al. 2001; Reynolds et al. 2003).

Certain antipsychotics have been shown to increase the susceptibility to developing diabetes mellitus, even in the absence of obesity. A meta-analysis examining second generation antipsychotics was conducted by Newcomer et al. (2005) using *no antipsychotic*, as one of the comparator groups. Patients receiving clozapine were shown to be almost 7½ times more likely to develop diabetes mellitus than those on no antipsychotics, and patients on olanzapine close to 2½ times more likely. One mechanism underlying this is the promotion of weight gain by antipsychotics, followed by insulin resistance. However, there are now data supporting a direct metabolic effect of antipsychotic medication. Olanzapine and clozapine have been shown to induce insulin resistance and impaired glucose tolerance even in the absence of obesity or family history of diabetes mellitus (Engl et al. 2005; Vestri et al. 2007). There may also be a contribution of increased risk of diabetes mellitus in people with schizophrenia from shared genetic predisposition (Gelder et al. 2006). However, it should be noted there have been studies *prior* to the advent of antipsychotic agents, describing an association between schizophrenia and elevated blood sugar levels and diabetes (Kasanin 1926; Braceland et al. 1945) suggesting that there may be additive or synergistic effects at work, since the introduction of antipsychotic medication.

In summary

Antipsychotic medication may contribute to the vulnerability of people with schizophrenia during an influenza pandemic by: (1) promoting obesity, which is a risk factor for poor clinical outcomes in influenza (and/or pneumonia), and (2) increasing the rates of serious medical comorbidities such as diabetes mellitus and ischaemic heart disease, which are associated with higher risk for medical complications from influenza and pneumonia.

1.6 Access to and utilization of heath care services

Following de-institutionalization, most people with schizophrenia in Australia are now treated in the community with relatively brief admissions to hospital, when required. There is an expectation that their lives will be as normalized and equitable as possible. Community and inpatient health services can be divided into public and private domains. The core components of public mental health services include: multidisciplinary community mental health teams (comprising psychiatrists, nurses, psychologists, social workers, rehabilitation workers and others); crisis assessment and treatment teams; hospital services, including psychiatric units for acute admissions as well as consultation liaison services; transitional step-up/step-down units; day care centres; dual disability services; rehabilitation units and services; and forensic services. Health care is also provided by the private sector including general practitioners, psychiatrists and psychologists, as well as non-government organizations and support programmes.

Despite these services, many people with schizophrenia do not receive the health care they require. Although more vulnerable to serious medical disorders, they have been found to have less access to general medical services, receive less preventative treatment (including fewer medications) for medical risk factors, and have reduced adherence to pharmacotherapy (Brown et al. 2000; Druss et al. 2001; Lambert et al. 2003; Kohn et al. 2004; Nasrallah et al. 2006; Newcomer & Hennekens 2007; Newcomer & Leucht 2011).

Comparison of Australia and the United States of America in health care and access

As much of the research into issues of health care and access for people with schizophrenia has been conducted in the United States (US), it is important to first make a comparison of the Australian and US health systems. There are both similarities and differences between Australia and the US in health care and access. The similarities are not surprising given the strong parallels between the two countries in terms of being industrialized nations with democratic multicultural societies, having strong historical links with Britain, having well organized and politically active health professionals, and having publicly visible health policy domains (Altman & Jackson 1991). Each country has also witnessed tragic massacres in relatively recent times (e.g. Port Arthur in Australia and Connecticut in the US), which have stimulated the public's interest in, and scrutiny of, mental health care. Both countries have a mix of publicly and privately funded health systems with similarities also in terms of categories of health care providers and settings. Mental health care providers in both countries broadly fall into four main groups - (1) clinicians who have

received specialized training in mental health care including psychiatrists, psychologist, and psychiatric nurses, (2) clinicians with training in general health care such as general practitioners/family physicians, nurse practitioners, (3) social services providers, and (4) informal volunteers (Sundararaman 2009). Settings in both countries include hospitals (public and private), community settings, and informal venues.

However, there are also significant differences in health care delivery and access between Australia and the US. Structural contrasts exist in terms of professional roles of doctors. In the Australian health care system, a patient's overall management is the role of the general practitioner, who is responsible for providing primary medical care (for mental and physical health problems) as well as directing referrals to specialists and allied health workers when required. The US health system has no exact equivalent to Australian general practitioner role, as US citizens have the option of self-referral to a specialist. In addition, certain 'specialties' (paediatrics, internal medicine, and obstetric and gynaecology) in the US system, unlike in Australia, provide *primary care* (Jones et al. 2011). A further structural difference in professional roles between Australia and the US is the existence of 'hospitalists' in the US. These medical practitioners work only in hospitals, managing the health care of inpatients, with direct referrals to 'subspecialists' when indicated. There appears to be increasing separation between their role and that of primary care 'family physicians' who work in community settings in the US (Jones et al. 2011).

Another important point of variance between the two countries is the extent of 'universal health care access'. In Australia there is a publicly funded universal health care scheme called Medicare (implemented in 1984), which coexists with the private health system. Medicare covers the cost of treatment in public hospitals and subsidizes clinical (medical as well as some allied health) consultations in the community, and investigations arising from them. Australian citizens (with exemptions for very low income earners) pay a 1.5% 'Medicare Levy' to help fund Medicare. In addition, there is subsidization of prescription medications for patients, provided by the government administered Pharmaceutical Benefits Scheme. If a private health provider charges above the 'scheduled (Medicare) fee', the patient will have to pay the 'gap' out-of-pocket. There is a choice for health care providers to 'bulk-bill' patients by charging only the scheduled fee, but at the time of writing, there is a government initiative for a $AU7.00 patient contribution ('co-payment'). The proportion of private practitioners who bulk bill varies between states but generally is low. The private health system in Australia is provided by organizations called *health funds*, the largest of which is a government-owned fund called Medibank. Medibank, with its highly regulated premiums, was a government initiative to attempt to limit the premiums set by 'for-profit' private health funds, by directly competing with them. The Private Health Insurance Act 2007 regulates private health funds which although are permitted to modify premiums based on a person's medical history and current health status, cannot discriminate in terms of premiums, benefits or membership on the basis of race, gender, religion, or sexual orientation. Private health funds provide

choices between different 'levels' of cover (which determine 'out-of-pocket' costs to the individual) and the option to select specific services to be covered.

The US does not provide universal health care access, and is essentially a two-tiered system (Wilper et al. 2009; Burns & Drake 2011). Funding of health care is predominantly through 'health care plans' with 'managed care'. Although these can be either government sponsored or privately based, health care facilities are largely owned and managed by private sector businesses. The US government funds programmes such as Medicare (established in 1965 for citizens aged 65 or older), Medicaid (to assist in the provision of health care to low income earners, also implemented in 1965), TRICARE, the Children's Health Insurance Program, and the Veteran's Health Administration. Although people under the age of 65 years who have a job are mostly insured by their employer (or a family member's employer), they can choose to purchase insurance. However, between 16-18% (over 40 million people) of Americans under 65 years are uninsured, and this may be a barrier to accessing health care (Levy 2014).

Uninsured people in the US have been found to be less likely to receive medical care and more likely to have poor health status (US Department of Health & Human Services. Agency for Healthcare Research and Quality. 2011). They are less likely to obtain screening and medical care for chronic conditions, more likely to suffer undiagnosed chronic conditions, and to received substandard medical care (Ayanian et al. 2000; Ayanian et al. 2003).

In addition, they are less likely to receive disease prevention care such as advice about diet and exercise, and influenza vaccination (US Department of Health & Human Services. Agency for Healthcare Research and Quality 2011). They report more problems obtaining health care, are sicker when hospitalized, are more likely to die during their hospital admission, and are diagnosed at later disease stages (US Department of Health & Human Services. Agency for Healthcare Research and Quality 2011). People with lower socio-economic status (over-represented in those with a mental illness such as schizophrenia) have been shown to be more likely to be uninsured. The proportion of people with health insurance is significantly lower for poor and lower-income earners, and about a third lower for people with less than a high school education than for people with a 'college' education. The 2004 Institute of Medicine Report found that uninsured adults had a 25% greater mortality risk than insured adults with health insurance accounting for an estimated 18,000 excess deaths every year in the US (Institute of Medicine 2004). A Harvard Medical School based study in 2009 estimated that close to 45,000 excess deaths occurred in Americans aged 18 to 64 years in 2005, associated with lack of health insurance (Wilper et al. 2009).

'Managed care' adds to the complexity of health care provision due to negotiations having to take place between payment bureaucracies and providers, on issues of eligibility and costs. This may impact on providers' and patients' clinical freedom and patient-doctor relationship (Zwar 2010). Ongoing initiatives are being explored by the US government to address these access

issues. For instance, a promising model, federally funded through the Health Resources Services Administration, is the system of Federally Qualified Health Centres, which comprise community health centres, school-based clinics, health centres for the homeless and migrant health centres. They have been designed as 'one-stop' comprehensive primary care sites, often including mental health services, dental services and pharmacies, in addition to providing medical care. 'Partial hospitalization' has been another energetically driven initiative in the US, with the aim of providing a less restrictive alternative to inpatient care in people with schizophrenia. Although there has been some evidence-based support for these in short term randomized clinical trials, few have persisted in the form they were intended to, with a tendency to become social support sites rather than maintaining a clinical focus.

A promising mental health reform initiative in Australia in recent years has been the implementation of early intervention programmes (EIP). These comprise separate multidisciplinary teams with a dedicated role of providing prompt treatment and psychosocial support, for people with first onset psychosis. The underlying rationale for this initiative is that there are poor outcomes when the duration of untreated psychosis is protracted (McGorry et al. 2007). EIP also place a strong emphasis and value on the provision of education and psychosocial support for the patient's family.

Challenges facing both the Australian and US systems include: need for better integration and less fragmentation in health service delivery, especially

between mental health services, drug and alcohol services and general medical services, but also between hospital-based and community based services; promotion of patient-centred care, with health services aiming to explore and meet the needs of the individual, with ongoing care through good communication and trust; removal of financial barriers for receiving high quality and provision of readily accessible health care; striving for better cultural competency especially for ethnic minorities; and better implementation of evidence-informed health care.

Disparities in health care and access for people with schizophrenia

The CATIE (Clinical Trials of Antipsychotic Treatment Effectiveness) study (Nasrallah et al. 2006; Newcomer & Hennekens 2007; Newcomer & Leucht 2011) found that among approximately 1500 people receiving treatment for schizophrenia (from 57 different academic and public sector treatment settings across the USA): 88% of patients with hyperlipidaemia were not receiving any lipid-lowering medication; 30% with diabetes mellitus were not receiving any anti-diabetic medication; and 62% with hypertension were not receiving any antihypertensive medication.

In a key epidemiological review of community-based health care, Kohn et al. (2004) demonstrated significant limitations in medical care for people with schizophrenia. They examined the world-wide (most World Health Organization [WHO] regions) extent of a 'treatment gap' for people with schizophrenia (and other mental illnesses), aged 15 years and older, by

reviewing epidemiological community-based surveys of service utilization published between 1980 and 2000. 'Service utilization' was defined as seeking health advice or treatment from any medical or professional service provider, including both public and private sectors, and specialized and non-specialized services, but excluding traditional healers and non-professional services. Median, as well as average, rates of service utilization were calculated to reduce statistical distortion from outliers. The median untreated rate ('treatment gap') for people with schizophrenia globally was 32.2% i.e. about one third of people with schizophrenia worldwide were untreated (for schizophrenia and medical comorbidity). Although this represents a wide treatment gap, the authors suggest that the figure is likely to be an underestimate because very few developing countries were included in their study (due to lack of data). Despite these concerning findings in service utilization, by Kohn et al. (2004), results from the 2010 Australian national survey of psychosis, reveal substantive links between people with psychosis and general practice settings, with 88.2% reporting that they had visited a general practitioner in the previous 12 months (Morgan et al. 2012).

As discussed earlier, untreated physical illnesses such as ischaemic heart disease increase the risk of complications from influenza. In a large cohort study (n = 88,241) of American Medicare patients aged 65 year and over (Druss et al. 2001), patients hospitalized for confirmed myocardial infarction were less likely to receive subsequent appropriate treatments such as a re-perfusion procedure (e.g. coronary artery stent), aspirin, beta-blockers or

angiotensin converting enzyme (ACE) inhibitors, if they suffered from a mental illness such as schizophrenia, compared to patients without a mental illness. In addition, there was a 34% increased risk of mortality within one year for patients with schizophrenia compared to patients without a diagnosis of a mental illness.

It has been argued that equality in health care for people with schizophrenia, and other serious mental illnesses, should be regarded as a basic human right (Fleischhacker et al. 2008). A human rights argument can be mounted on the grounds that people with a higher burden of medical illnesses, such as people with schizophrenia, are entitled to greater use of health care services given their higher levels of health needs (Lawrence & Kisely 2010). There are several reasons for this disparity in access and delivery of quality health care to people with schizophrenia compared to people without a mental illness. On a broad level, Cartesian dualism has, and continues to, exert a profound effect on medical thinking and attitudes in Western countries (Fabrega 1990; Sharpe 1998). Although Hippocrates believed in a 'mind in the body' approach, in the post-Descartes era people are often rigidly classified as being *either* mentally or physically ill, as if they are mutually exclusive, despite the strong links between psychiatric and physical illness. This is sometimes reflected in the structure of health services, both architecturally and operationally, with unhelpful separation of mental and physical health services, rather than the employment of an integrated care model.

In addition to the influence of Cartesian dualism, there are reports in the literature of more specific factors acting as barriers to people with schizophrenia accessing and utilizing the health care they need. Jeste et al. (1996) identified cognitive impairment exhibited by people with schizophrenia as negatively impacting on awareness of physical problems. In addition, they drew attention to pain, which they recognized may be masked by a high pain tolerance in people with schizophrenia. This is likely to disadvantage patients with schizophrenia during a pandemic influenza by a reduction in important warning symptoms such as sore throat or pleuritic pain. Jeste et al. also identified physician related factors, which impact on the recognition and management of medical disorders in people with schizophrenia. These included psychiatrists being focused purely on psychiatric issues to the exclusion of physical complaints, as well as physical symptoms being regarded as psychosomatic. Goldman (1999) identified the following as negatively impacting on the delivery of quality health care for people with schizophrenia: fragmented health care systems; reluctance of medical specialists to treat people with serious mental illness; changes of treating physician; poor access to general health services; and patients' inability or reluctance to communicate physical symptoms. Goldman advocates an assertive approach to combat these factors including: actively seeking a history of physical symptoms rather than waiting for a patient to spontaneously disclose them; regular and comprehensive physical examinations; ensuring that recommended treatments are understood by patients; and promoting the involvement of family and friends in assessment and treatment processes. Lambert et al. (2003) concur

with the factors identified by Jeste et al. and Goldman mentioned above, but report additional contributors to poor medical care for people with schizophrenia, including: perception by psychiatrist that physical problems should be dealt with by referring doctors; lack of adequate follow-up due to itinerancy and lack of motivation; and difficulty in comprehending medical advice. In addition, **trust** plays a core role in the doctor-patient relationships. Mistrust has been not only associated with less utilization of health care services, but also with other negative health outcomes such as reduced adherence to management advice, poorer perceived effectiveness of care, less continuity of care, poor therapeutic alliance with more disputes between doctor and patient, and poorer self-reported health (Mechanic & Schlesinger 1996; Thom et al. 1999; Pearson & Raeke 2000; Hall et al. 2001; Thom et al. 2004; O'Malley et al. 2004; Musa et al. 2009).

In summary

Despite having higher rates of serious medical disorders, people with schizophrenia have less access to general medical services, receive less preventative treatment for medical risk factors, and have reduced adherence to medical therapy, compared with people in the general population. As a vulnerable population, people with schizophrenia require high quality health care delivery in terms of both promotion of preventative measures as well as prompt medical assessment, and assertive treatment if indicated, during a pandemic influenza.

1.8 Conclusion

Most people with schizophrenia now live and are well supported in the community with an expectation of equity in health care and promotion. However, they are a potentially vulnerable group with respect to influenza, especially during a pandemic. Their heightened risks arise from a combination of factors including: significant medical comorbidity; increased prevalence, compared with the general population, of obesity and potentially harmful life style factors, especially smoking and excess alcohol consumption; adverse effects of psychotropic medication; and poor access to, and engagement with, health services. A framework of these factors is shown in Table 1.6. A public health approach is required to address this vulnerability of people with schizophrenia to influenza. While this is important for seasonal influenza, a particular focus on pandemic influenza is highly appropriate due to the very significantly increased threat it delivers. Core components of a targeted public health approach include investigation into how people with schizophrenia: (1) receive information about a serious influenza outbreak, (2) perceive the risks associated with pandemic influenza, and (3) what they would be prepared to do about reducing those risks, especially in terms of protective behaviours. The next chapter reviews the literature relating to the relevant aspects of health information sources, risk perception, and protective behaviours, including the relationship between risk perception and willingness to adopt protective measures.

Table 1.6 Framework of vulnerability factors

Lifestyle Factors
▪ Increased rates of smoking ▪ Increased rates of alcohol misuse (± illicit substance use) ▪ Increased rates of obesity (secondary to both over-eating and under-exercising)

Comorbid Medical Disorders
▪ Chronic obstructive pulmonary disease ▪ Ischaemic heart disease ▪ Diabetes mellitus type II

Health Services Factors

General factors
▪ Shortage of general practitioners (in Australia)
▪ Lack of time and resources encouraging physical health evaluation in public mental health settings
▪ Mental health services often separated from general medical services both architecturally and operationally

Doctor-related factors
▪ Ambivalence of medical clinicians to being involved in the care of people with serious mental illness
▪ Physical symptoms assumed to be purely somatization (or delusional)
▪ Assumption by psychiatrists that physical health issues will be managed solely by general practitioners (and that psychiatrists have no role in this)
▪ Mistrust in doctors impacting on the quality of the doctor-patient relationship

Social factors impacting on health services access
▪ Unstable accommodation (esp. homelessness / itinerancy)
▪ Unemployment
▪ Poor educational attainment
▪ Social isolation (poor or absent social support network; increased likelihood of living alone)

Mental Illness Factors
▪ Psychotropic medication associated with obesity and type II diabetes mellitus ▪ Negative syndrome of schizophrenia (esp. amotivation, asociality) ▪ Positive symptoms of schizophrenia (esp. paranoia, thought disorder) ▪ Cognitive impairment (e.g. memory, organization) ▪ Reduced pain perception

CHAPTER TWO

PANDEMIC INFLUENZA: INFORMATION SOURCES, RISK PERCEPTION

AND PROTECTIVE BEHAVIOURS

2.1 Introduction

This chapter further develops the background to the rationale of the thesis

research study. In addition to the vulnerability issues discussed in the previous

chapter, clinical risks associated with influenza, for both people with

schizophrenia as well as for people in the general population, are likely to be

increased during a pandemic due to the paucity or absence of natural immunity

against a novel virus. It is also a time when medical services, including general

practices, hospital emergency departments, and intensive care units, are likely

to be pushed to the limit of their capacity, accentuating the importance of

health service access issues for people with schizophrenia (described in

chapter one) and potentially increasing their vulnerability.

An overview of the relevant aspects of pandemic influenza is presented in this

chapter. As the thesis study is based on an Australian population, the

framework for the management of pandemic influenza is the response plan

developed for this setting (but also reflecting key WHO directions), the

Australian Health Management Plan for Pandemic Influenza (AHMPPI)

(Australian Government, Department of Health and Aging. Australian Health

Management Plan for Pandemic Influenza 2009). Two core recommendations

in this plan are: **(1)** ***effective communication of accurate and up-to-date***

information to the public (as well as to health professionals and officials), and

(2) ***implementation of strategies to reduce viral transmission***. These

recommendations further underpin the basis for the thesis research project.

With respect to the first recommendation, there is a dearth of research

exploring how people with schizophrenia obtain information on health matters.

Knowledge of how they access health information is important because it will

inform on planning for effective communication during an influenza pandemic,

as well as for health issues more broadly. A brief literature review of the

relevant aspects of health information sources is included in this chapter.

Regarding the second AHMPPI core recommendation, it is important to try to

understand how people with schizophrenia view the risks associated with a

pandemic influenza and what they are prepared to do about those risks, in

order to try to reduce viral transmission during a pandemic influenza,

particularly with respect to protecting their own health. Risk perceptions and

Figure 2.1 Role of risk perceptions in health outcomes
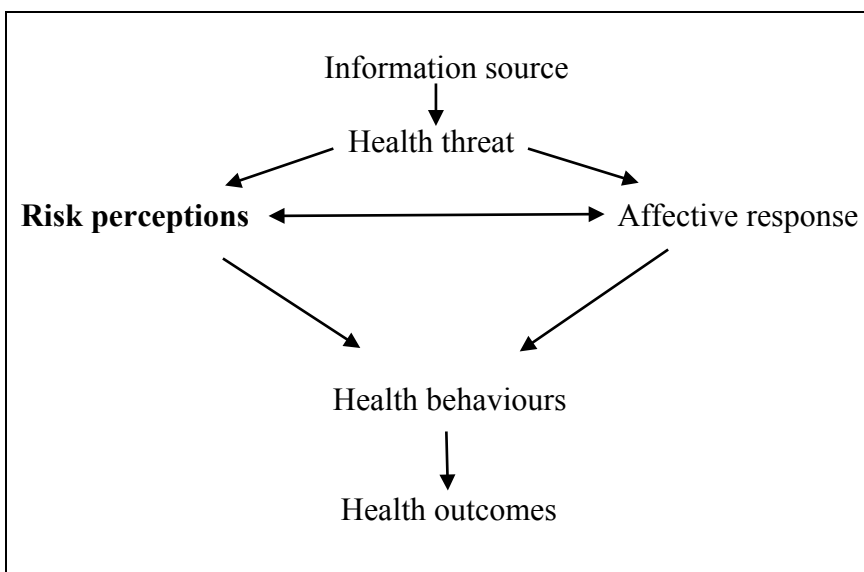
associated affective responses, influence health *behaviours*, which in turn impact on health *outcomes* (Figure 2.1) (Leventhal et al.1984; Slovic 2000; Brewer et al. 2007; Petrie et al. 2007).

This chapter also presents a literature review of the relevant general aspects of the perception of risk followed by an examination of risk perception studies specifically pertaining to pandemic influenza (and avian influenza outbreaks). This in turn is followed by a review of the scientific literature on protective behaviours against contracting influenza, including perceived barriers, and the relationship between risk perceptions and willingness to adopt protective measures.

2.2 Pandemic influenza

Brief historical context

The ability to confirm an outbreak of respiratory disease as 'influenza' was enabled by the isolation of an influenza virus by Richard Shope in 1930 (Taubenberger 2006). However, reports suggestive of influenza date back to antiquity, with early Greek writings occurring in 412 BC. The first influenza pandemic is likely to have occurred in 1510, spreading from Africa to Europe (Potter 2001). An outbreak of respiratory disease occurring in 1580 was almost certainly an influenza pandemic. It spread from Asia to Africa, completely engulfed Europe over a six month period, with 8000 deaths in Rome alone, and ultimately reached America (Pyle 1986). There appear to have been two

influenza pandemics in each of the 18th (1729 and 1781-1782) and 19th

centuries (1830-1833 and 1898-1900).

More recent pandemics and current threats

More recent influenza pandemics are summarized in Table 2.1. Particularly

catastrophic was the 'Spanish flu' of 1918-19, which killed more people in 24

Table 2.1 Features of influenza pandemics in the 20th and 21st centuries

Pandemic	Area of emergence	Viral subtype	Estimated case fatality rate	Estimated excess mortality worldwide
1918-1919 'Spanish flu'	Uncertain ? Kansas, USA	H1N1	2-3%	40-50 million (? 50-100 million)
1957-1958 'Asian flu'	Southern China	H2N2	< 0.2%	2 million
1968-1969 'Hong Kong flu'	Southern China	H3N2	< 0.2%	1 million
2009-2010 'swine flu'	Mexico	H1N1	≤ 0.01%	25,000

weeks than the AIDS (Acquired Immune Deficiency Syndrome) epidemic has

in over 24 years, and more than all people (soldiers and civilians combined)

killed in the First World War (Barry 2005). In recent times concern has turned

to the possibility of an avian influenza pandemic. Human infection with the

highly pathogenic H5N1 strain has a case fatality rate of about 60% (World

Health Organization 2011). Even though currently there is minimal capacity for

human-to-human transmission, genetic re-assortment or adaptive mutation

may change this, rendering this H5N1 strain a very significant world threat.

Pandemic influenza preparedness and response planning

Pandemic influenzas are recurring and continually evolving threats that appear to break out at 10-50 year intervals. Therefore, there is a need to monitor for their emergence and progress. The Australian Government Department of Health and Aging (DoHA) has an ongoing role with WHO in an international network of surveillance of pandemic influenza risk by monitoring for the overseas emergence of novel influenza viruses that have the potential to spread rapidly between humans and cause a pandemic. A set of influenza pandemic alert levels to describe the global situation at a given time was developed by WHO in 1999 and revised in 2005 (Figure 2.2, Table 2.2). Phases 1-3 relate to capacity development and response planning, while phases 4-6 signify the need for execution of response to mitigate harmful effects of the outbreak. Following phase 6, there are two further phases - post peak, with the possibility of a second or third wave, and post pandemic.

Figure 2.2 WHO Pandemic Influenza Phases (adapted from WHO 2011**)**
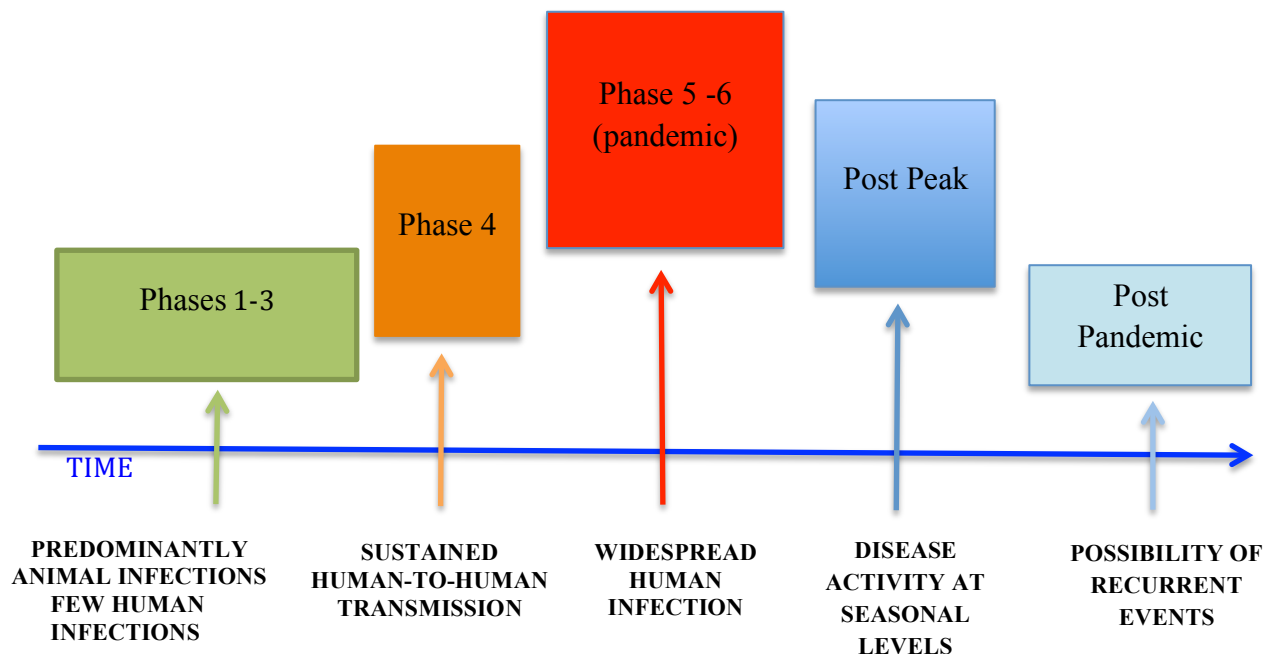
Table 2.2 WHO pandemic phase description (adapted from WHO 2009)

Phase 1	No influenza virus circulating among animals has been reported to cause infection in humans	Uncertain
Phase 2	An animal influenza virus circulating in domestic or wild animals is known to have caused infection in humans and is therefore considered a specific potential pandemic threat	Uncertain
Phase 3	An animal or human-animal reassortant influenza virus has caused sporadic cases or small clusters of disease in people, but has not resulted in human-to-human transmission sufficient to sustain community-level outbreaks	Uncertain
Phase 4	Human-to-human transmission of an animal or human-animal influenza reassortant virus able to sustain community-level outbreaks has been verified	Medium to high
Phase 5	The same identified virus has caused sustained community-level outbreaks in at least two countries in one WHO region	High to certain
Phase 6	In addition to the criteria in Phase 5, the same virus has caused sustained community-level outbreaks in at least one other country in another WHO region	Pandemic in progress

Epidemiological models predict that, in the absence of adequate intervention, a future influenza pandemic may result in up to 7.4 million deaths globally, with 40% of Australia's population showing clinical evidence of infection (Australian Government, Department of Health and Aging 2009). Assuming a case fatality rate similar to that of the Spanish influenza described earlier (i.e. 2.4%) this would result in the deaths of approximately 200,000 Australians (Australian Government, Department of Health and Aging 2009). Therefore, it is essential that health services are maximally prepared with a well-considered response plan. It has been estimated that an effective response plan, including the implementation of protective measures mitigating spread of the virus, has the capacity to reduce the proportion of people clinically affected to 10% and halve the case fatality rate, with a corresponding reduction in the number of deaths

to 25,000 Australians (Australian Government, Department of Health and Aging 2009).

The Australian Government's strategies for dealing with a pandemic influenza are outlined in the Australian Health Management Plan for Pandemic Influenza (AHMPPI) (Australian Government, Department of Health and Aging. Australian Health Management Plan for Pandemic Influenza 2009). This was developed and formulated by the Office of Health Protection in the Department of Health and Ageing following comprehensive consultation with peak bodies, advisory groups and health experts in pandemic influenza. The 2008 document was updated in December 2009 in the light of new evidence relating to the H1N109 pandemic. The phases of the recommended response to a pandemic influenza are summarized in Table 2.3.

The PROTECT phase was introduced as a consequence of finding that the causative viral strain in the H1N109 pandemic had a lower case fatality rate ($\leq 0.01\%$) than a typical seasonal influenza. However, despite the virus producing only mild illness in most sufferers, certain vulnerable groups were found to exist. These included people with a comorbid medical illness or obesity, people of indigenous cultural background, immunosuppressed patients, and pregnant women. The aim of this new AHMPPI phase was to *protect* these vulnerable groups, with a heightened focus on preventative measures, early identification of the illness and prompt treatment (e.g. with antiviral medication).

Table 2.3 Phases and corresponding responses of AHMPPI (adapted from WHO 2009)

Phase	Description	Response
Alert	Novel virus with pandemic potential causes severe disease in humans who have had contact with infected animals. No effective human-to-human transmission. Novel virus has not arrived in Australia	Being vigilant for a future pandemic Support overseas response to control source Preparedness and response planning Stock-piling vaccinations and antiviral medication
Delay	Novel virus has not arrived in Australia but clusters of cases have occurred in at least one overseas country	Delay the entry of the virus into Australia *Pre-border*: support overseas response to control source; reduce number travellers from high risk areas entering Australia; advise Australians against visiting high risk areas abroad *Border*: screen to detect infected or high risk travellers; quarantine when necessary
Contain	Pandemic virus has arrived in Australia causing a small number of cases and or clusters	Reduce spread of the virus: voluntary home isolation if infected with mild illness, and social distancing; wearing a surgical facemask; good personal hygiene (including hand washing) and cough etiquette
Protect	A pandemic virus which is mild in most but severe in some is established in Australia	Protect (i.e. identify and treat early) vulnerable groups (indigenous, comorbid medical illness, obese, pregnant women, immuno-suppressed) and their carers
Sustain	Pandemic virus is established in Australia and spreading in the community	Sustain the response while awaiting the development of a vaccine
Control	Customized pandemic vaccine widely available and is beginning to bring the pandemic under control	Control the transmission of the virus with a vaccine
Recover	Pandemic controlled in Australia but further waves may occur if virus drifts or is re-imported into Australia	Return to normal while remaining vigilant

The AHMPPI identifies four key *operational objectives* to guide and focus the health sector response during a pandemic. They are:

(1) *Communication of the latest and best information to the public, health professionals and health officials involved in decision-making.* Viruses causing a pandemic influenza may vary considerably in their virulence and, therefore, there needs to be flexibility in the health sector's and community's

response depending on the most up-to-date information during the course of an outbreak.

(2) Implementation of strategies to reduce viral transmission and, therefore, minimize the number of people affected. These include assisting overseas infection control activities, border protection measures to delay the entry of the causative viral strain into Australia, and the promotion of preventative measures including infection control strategies (hand hygiene, social isolation/distancing and wearing a face mask) and vaccination and anti-viral medication.

(3) Priming heath services to minimize mortality and morbidity. Measures include providing surge capacity in the health workforce, establishing dedicated influenza services and maintaining life-saving services such as intensive care units.

(4) Working in partnership across all sectors of government to support the whole of government aim of protecting Australians and reducing the impact of a pandemic on social functioning and the economy.

Although all four objectives are important, the first two are particularly relevant to the thesis research project. With respect to the first operational objective, it is important to know how people with schizophrenia acquire health information, and the level of trust they invest in given information sources, in order to deliver helpful and timely information about the influenza pandemic (including recommended protective measures). There is a dearth of research evaluating how people with schizophrenia access health information. The AHMPPI posits "no matter where we live or what we do, we all need accurate and timely

information so that we can work together to protect our country and ourselves" (Australian Government, Department of Health and Aging. Australian Health Management Plan for Pandemic Influenza (2009) p. 37.)

As indicated in Operational objective 2, once a pandemic influenza reaches Australia, the goal of the health sector is to try to reduce its spread, especially in the early stages of the pandemic. The promotion and implementation of protective measures is particularly important for people with schizophrenia who have increased risks of poor clinical outcomes in the event of contracting influenza during a pandemic, and is a core focus of the thesis research project. The efficacy of, and perceived barriers to, **vaccination**, increased **hand washing**, **self isolation** and wearing a surgical **face mask** will be discussed later in this chapter.

Australia's response to the H1N109 pandemic

The WHO informed Australian Health Authorities on 24 April 2009 of a new strain of influenza A in Mexico, USA, Canada and Europe (Gallego 2009). The virus subsequently spread rapidly around the world and the first case in Australia was confirmed on 9 May 2009. By early June Australia had laboratory confirmed cases in every state and territory. The WHO declared the human swine influenza outbreak a *pandemic* on June 11 2009.

The initial reports from Mexico suggested the H1N1 strain was associated with a high mortality rate. Therefore, the Australian government launched the

DELAY phase, with implementation of border control measures including active surveillance for potential incoming cases of swine influenza, with health screening and health declarations of passengers arriving in Australia. On May 9 2009 Australia moved to the CONTAIN phase as there was evidence that the virus being transmitted within the community. Public messaging promoted simple infection control measures such as hand washing, and self-isolation at home if infected. The CONTAIN phase also involved the release of the national stockpile of anti-viral medication (oseltamavir). When it became clear that the H1N1 virus was not as virulent as initially thought, Australia changed its response to the PROTECT phase described earlier. Although most people enjoyed a rapid and full recovery from swine influenza, about 2% of infected individuals rapidly progressed to life-threatening acute respiratory distress syndrome and multiple organ failure. Many (but not all) of these people had an underlying medical disorder. Following the SUSTAIN phase, a national vaccination programme was launched on 30 September 2009 using a monovalent vaccine. This marked the beginning of the CONTROL phase.

The acute health impacts of swine influenza in Australia lasted about 18 weeks, ending in September 2009. However, it was not until 10 August 2010 that the WHO Director-General, Dr Margaret Chan, announced entry into the post-pandemic phase.

There were 37,636 laboratory confirmed cases in Australia of swine influenza in 2009 (with 191 associated deaths). However, this does not represent the

true incidence of swine influenza because laboratory testing was not universally carried out, and given the mild nature of most presentations, many people with influenza symptoms are likely to have not attended a health service.

Even though there has been support from health professional bodies (such as the Australasian Society for Infectious Diseases) for the enactment of AHMPPI during the 2009 swine influenza pandemic, there has also been commentary on limitations in Australia's response and how it could be improved for future outbreaks (Gallego 2009; Collignon 2010). For instance, Collignon (2010) expressed the following concerns/ suggestions:

(1) There was a need for a reduction in viral transmission rates by placing more emphasis on simple infection control measures (hand hygiene, self-isolation, masks, gloves) rather than a focus on vaccination and antiviral medication, especially as effective vaccines are only available after much of the negative impact has already occurred.

(2) There was a need for better communication to the public regarding what action to take if symptoms occur; disproportionate fear evoked by the media resulted in unnecessary attendance at hospital emergency departments or general practices, reducing access for individuals in vulnerable groups (or anyone) with serious illness.

These recommendations reinforce two core themes of this thesis – how people with schizophrenia access health information and the importance of infection control protective measures.

In summary

Influenza pandemics are recurring and continually evolving public health threats that appear to develop every 10-50 years. Although they vary in their degree of lethality, those caused by hypervirulent strains have the capacity to take a very large number of human lives in a relatively short passage of time. Therefore, it is essential that health services are maximally prepared with a well-considered response plan. Key strategies aimed at mitigating the negative impact of a pandemic influenza include the communication of up-to-date, accurate and relevant information to the public and to health professionals, the adoption of protective measures against the causative viral strain, and optimizing health delivery. Vulnerable groups, such as people with schizophrenia, require a special focus of protection in the event of a pandemic influenza.

2.3 Use of and trust in health information sources

Use of health information sources

Health information sources now enable the general public to take an active role in their own health care more than in any other period in history (Rains 2007). In addition to consultation with a doctor, the Internet, television, radio,

magazines, newspapers, and family and friends have assisted individuals in being informed and empowered about managing their health (Brashers et al. 2001; Anderson 2004; Dolan et al. 2004; Rains 2007). During a pandemic influenza it is important that relevant and accurate health information is accessible to the general population, and to vulnerable groups, in order for the public to have a awareness of their risks and to know what they should do in the circumstances. In order to evaluate how to most effectively deliver this information it is necessary to ascertain what information sources people use to acquire health information and their levels of trust in these sources.

To the best of the candidate's knowledge there have been no studies carried out examining what information sources people with schizophrenia use to acquire health information, either generally or in the context of pandemic influenza. However, there are studies exploring the general population's use of information sources to obtain health information about outbreaks of respiratory disease.

Jones & Salathe (2009) conducted an online survey of risk perception and behavioural responses to the 2009 H1N109 pandemic, in the general population. They included in their questionnaire an item exploring what information sources participants used to obtain information about the pandemic. Volunteers were asked to rate how frequently they used the Internet, radio, TV, a health official, friends or a social networking tools (e.g. Facebook, Twitter) as an information source on the pandemic. A Likert scale

was used, with response options ranging from *1 = never use as an information source*, to *5 = frequently use as an information source*. The most frequently used information source was the Internet (mean score approximately 3) and the least, social networking tools (mean score approximately 0.7). The other information sources were statistically indistinguishable from each other (each with a mean score of approximately 1.5). An obvious shortcoming of this study is the self-selection bias in the study population sample i.e. access to a device with Internet connection was required to participate in the study. In this respect, the result of the Internet being the most commonly used information source is not surprising.

Gray et al. (2012) conducted a qualitative study in New Zealand exploring community responses to key government health messages about H1N109. Part of this study examined information sources used. Although participants reported acquiring health information about 'swine flu' from newspapers, television, radio and the Internet, most information was received from their workplace and/or the community (which included family and social networks, 'regular forums and meetings', church groups and health centres). This is at variance with two earlier studies. An American study by Janssen et al. (2006) found that the Internet ('Google') was the primary source of information about pandemic influenza (for both the general public and health care providers). In a study of the general population in the United Kingdom, Gupta et al. (2006) found that 68% of respondents cited television as their preferred means of receiving information during a pandemic.

Brug et al. (2003) conducted an electronic survey of 373 respondents drawn from a random sample of 500 members of an Internet Research Panel, in the Netherlands during the 2003 SARS outbreak. Data were collected using Likert scale responses, ranging from *1 = very little* to *5 = very much*, to a questionnaire item enquiring how much information about SARS participants obtained from various information sources, including television, newspapers, the Internet, magazines, health officials, friends and physicians. They also enquired about the level of confidence participants had in each of these sources, again using a 5-point Likert scale. The authors obtained the mean of the Likert responses of all participants and found that television had the highest ranking, and newspapers the second highest ranking, for both amount of information obtained and level of confidence (see Table 2.4). Although the

Table 2.4 Sources of information about SARS (mean Likert response and 95% confidence intervals) - adapted from Brug et al. (2004) Emerging Infectious Diseases Vol. 10 p. 1486

Information	Amount of information	Level of confidence
Television	3.9 (3.8 – 4.0)	3.6 (3.5 – 3.7)
Newspapers	3.5 (3.3 – 3.6)	3.4 (3.3 – 3.5)
Internet	2.3 (2.2 – 2.5)	3.0 (2.9 – 3.1)
Magazines	2.1 (2.0 – 2.3)	2.7 (2.6 – 2.8)
Health Officials	1.7 (1.6 – 1.8)	3.3 (3.2 – 3.5)
Friends	1.6 (1.5 – 1.7)	2.5 (2.3 – 3.6)
Physicians	1.3 (1.2 – 1.4)	3.2 (3.1 – 3.4)

Internet was the third ranked information source for amount of information gained about SARS, it was fifth in terms of level of confidence in it. Physicians had the lowest rank for amount of information but were ranked fourth in terms of level of confidence.

In contrast to this Dutch study were the findings of an Australian study (n = 52) conducted by Dart et al. (2008), examining what information sources people in three disparate communities (low socio-economic, mid-high socio-economic, and a university, in Queensland) reported obtaining their general health information from. These sources included local doctor, television, family and friends, health pamphlets in doctors' waiting room, newspaper, magazines, allied health practitioner, alternative therapy practitioner, the Internet and radio. These particular information sources were identified in the first phase of this study using semi-structured interviews and focus groups. In phase 2 of the study, paper-based surveys were provided in community organizations and local health practices. In all three communities, 'local doctor' was the highest ranked source in terms of how participants obtained most of their health information, as well as being the most trusted health information source. Family and friends ranked in the top three sources for amount of information obtained on health matters in all three communities, as did television for the low and mid-high socio-economic communities.

Trust in health information sources

Trust in an information source is a core component of an effective health promotion and risk communication process, especially when there is an element of uncertainty about the health threat, which is frequently the case with an outbreak of respiratory infection caused by a novel virus. Trust is a *multidimensional* construct. A trustworthy information source delivers a message that is *accurate* and *reliable*, and demonstrates *honesty*, *competence* and *impartiality* in the communication of the message.

At the time of writing, a review of the scientific literature did not reveal any studies exploring levels of trust people with schizophrenia have in health information sources. However, there are studies exploring trust in information sources in the general population. A key study is that by Hesse et al. (2005), who used data from a US telephone survey of 6369 participants aged 18 or older. Volunteers were surveyed on their use of, and trust in, health information sources which included physician, the Internet, television, family or friends, magazines, newspapers and radio. With respect to trust the study focussed on information about cancer. Physicians were the most highly trusted information sources with 62.4% of participants reporting 'a lot' of trust in their physicians, followed by the Internet (23.9%), television (20.0%), family or friends (18.9%), magazines (15.9%), newspapers (13.1%) and, the least trusted, radio (9.9%). There were correlations between the levels of trust in health information sources and several socio-demographic variables. Women were more trusting than men for all information sources, but particularly with respect to physicians

(odds ratio = 2.1; 95% confidence interval 1.4 - 3.3) and least for the Internet (odds ratio = 1.2; 95% confidence interval 1.0 - 1.5) and radio (odds ratio = 1.2; 95% confidence interval 0.9 - 1.4). Except for family or friends, people in a younger ager group were more trusting of health information sources than those in an older age group i.e. those aged 18-34 years were more trusting than those aged 36-64 years, who were more trusting than those aged ≥ 65years. This correlation between age and level of trust was most marked for the Internet, with adults aged 18-34 being ten times more likely, and adults aged 35-64 five times more likely, to report 'a lot' or 'some' (versus 'little' or 'not at all') trust in the Internet than those aged ≥ 65. Level of education was also a predictor of level of trust in most health information sources. For instance, participants who had completed their high school education or achieved a higher level of educational attainment were more trusting of the Internet, magazines, and newspapers compared with people with less than a high school education. Interestingly, when asked about their preferred information sources for specific health information ('cancer'), 49.5% revealed that they "wanted to go to" their physician first. However, when asked what they *actually* did, 48.6% reported going online first, with only 10.9% going to their physician first. The study found that 63.0% of participants reported that they had used the Internet (for any reason) at some time in their lives. The commonest reason for going online for these volunteers was to acquire health information, with 63.7% of online participants revealing that they had searched online for health or medical information in the preceding twelve months.

There were both similarities and differences to the Hesse et al. findings in a New Zealand study by Lawson et al. (2011). The survey was mailed to a random sample of adults from the electoral roll. A response rate of 61% yielded 8,291 participants. Median trust scores for health information sources were calculated from Likert responses that ranged from, *1= don't trust at all* to *5 = trust a lot*. Among the sources relevant to this thesis, doctor ranked the most trusted source, with a median score of five. Family, friends, the Internet, magazine articles, newspaper articles, television programmes and radio programmes, all had a median score of three. Women expressed more trust than men in all of the information sources. Trust in media sources declined with aged, but trust in doctors increased with age. Unlike the Hesse et al. (2005) study, trust in media health information sources was lower in participants with higher levels of education. Ethnicity was also a predictor of reported level of trust. Media sources were rated mostly highly in terms of being trustworthy, by Chinese, Indian and 'other Asian' ethnic groups. Friends and family were seen as less trustworthy by New Zealanders with a European cultural background. In the study of information sources reporting SARS, by Brug et al. (2004) described above, a somewhat surprising result is that newspapers ranked first as the information source participants reported most confidence in, with physicians, ranking fourth behind newspapers (ranked second) and health officials (ranked third). A possible explanation for this finding is that doctors may be perceived as not keeping up to date with new health events such as SARS. The study of three disparate communities by Dart et al. (2008), described above, found that for all three communities the

rank order of relevant information sources, in level of trust (from highest to lowest) were: local doctor, family and friends, the Internet and television. The remaining media sources (newspaper, radio and magazines) were very similar to each other in their 'trust scores' and between communities.

In Summary

Access to trusted information sources is important to empower people to play an active role in managing their health, including choosing to take protective actions against emerging threats such as a pandemic influenza. There are no studies examining how much health information people with schizophrenia (who are especially vulnerable to health problems) acquire from given sources, and the level of trust invested in these sources. Although studies of the general population frequently show doctors as important and trusted sources of health information, there is also research which has found television, newspapers and the Internet used and trusted more than physicians as sources of information on SARS.

2.4 The perception of risk

Introduction

The previous sections of this chapter have established the potential for significant harm that a pandemic influenza can inflict on a community and that an important strategy in mitigating this harm is the adoption of protective

measures to reduce viral spread. One of the determinants of what people are prepared to do about a health threat is how they perceive risks associated with that threat. It is important to understand and discuss with people their risk perceptions associated with a pandemic influenza, as these have the capacity to shape and influence protective health behaviours. Risk perceptions are important components of most health behaviour theories including the Health Belief Model (Rosenstock 1974), the Self-Regulatory Model (Leventhal et al. 1984), the Theory of Reasoned Action (Fishbein & Ajzen 1975), the Theory of Planned Behaviour (Ajzen 1985) and the Social Cognitive Theory (Bandura 1994).

A recent meta-analysis examined the relationship between risk perceptions (perceived likelihood, perceived vulnerability and perceived seriousness of contracting various infectious diseases, including influenza) and the protective health behaviour of receiving a vaccination against each infectious disease (Brewer et al. 2007). The authors concluded: "The consistent relationship between risk perceptions and behaviour, larger than suggested by prior meta-analyses, suggest that risk perceptions are rightly placed as core concepts in theories of health behaviour" (Brewer et al. 2007, p.136). The authors also found that there was a greater correlation between risk perception variables and protective health behaviour in the better quality studies i.e. in those that were prospective, had higher quality risk measures, or had unskewed risk or behaviour measures.

This section of chapter two, will discuss the relevant general aspects of risk perception as a background for, and providing a context to, pandemic influenza risk perception.

Definition

Although there is no universally accepted definition of risk perception, most conceptualizations involve two essential components – *uncertainty* and a *negative outcome.* It could be argued that if an adverse outcome were absolutely certain it would not generally be referred to as a 'risk' but rather as a consequence. Therefore, risk perception could be defined as a person's subjective assessment of the *likelihood* of, *susceptibility* to and *severity* of*,* an adverse outcome, in the face of a particular threat (Brewer et al. 2007).

The psychometric paradigm

A very significant advance in the research of risk perception involved work by Paul Slovic et al. (1982), which sought to explore the cognitive processes involved in risk perception. These researchers employed cross-sectional survey methods for examining *expressed preferences.* Some of the characteristics, or dimensions, of risks, which the psychometric paradigm has explored, include: voluntariness, immediacy, precise knowledge of the possible adverse outcome versus a relatively *unknown outcome*, chronic versus catastrophic (i.e. kills one person at a time versus a large number of people at once), associated feeling of *dread,* severity of consequences (i.e. magnitude of negative outcome) and level of control over the risk (e.g. vaccination available

against pandemic influenza) (Slovic 2000). After asking lay people to rate their perceived risks of a number of events on these dimensions, a factor analysis was performed. Among the above factors, *a feeling of dread* (and also *unknown outcome*) appeared to explain a very significant amount of the variance in the rating of risk. This led to another significant step forward in the understanding of risk perception – the recognition that in addition to cognition, *affect and emotion* play an important role. Finucane et al. (2000) have posited that risk is perceived in two core ways – 'risk as analysis' and 'risk as feelings'. The former refers to the slower, deliberate use of logic and reason to assess the risk elements inherent in a given situation, including both expectancy (i.e. perceived probability) and value (i.e. perceived severity). 'Risk as feelings' represents the rapid, automatic, intuitive and instinctive reactions and emotional responses to perceived danger. Finucane et al. (2000) carried out a study where affect was manipulated by different kinds of information about three technologies. They found evidence that affect plays a role in influencing cognitive judgements of risk and benefits, and vice versa. If favourable information about a technology was presented to the participants, suggesting benefits, a positive affect was engendered and participants were more likely to perceive the risks as low. Conversely, if unfavourable information was presented, suggesting a lack of benefits and producing a negative affective experience, participants were more likely to report the risks as high.

Risk identification and risk judgement

Risk perception and its assessment may relate purely to whether a person perceives any risk at all in a given situation (regardless of any estimates of the magnitude of this risk) e.g. "Does smoking result in risk?" This has been usefully denoted by the term *risk identification* by some authors (Millstein & Halpern-Felsher 2002). It has been extended to involve an identification of any potential consequences if a given situation is perceived as involving risk e.g. "What could happen if you smoke?" On the other hand, the term *risk judgement* has been used in the literature to reflect a person's estimate of the *magnitude* of risk. Furthermore, this has been subdivided into *conditional* and *non-conditional* risk judgements depending on whether there is an associated antecedent condition or behaviour which might modify the person's perception of risk inherent in a situation e.g. "What do you see as your risk of contracting the flu this winter?" (non-conditional) versus "What do you see as the risk of contracting the flu this winter if you weren't to receive a flu vaccination?" (conditional). Much research has been marred by not framing the *conditional* form of the question and therefore being deprived of an accurate interpretation of the participant's perception of risk. For example, if a person answered "low" to the question, "What do you see as your chances of contracting the flu this year", they may perceive the overall risk as low and therefore not see the need for a vaccination. On the other hand, they may perceive the risk as high without vaccination but view vaccination as highly protective and intend to have one, and therefore answer "low" in this context. These are clearly two very different risk perceptions.

Risk perception measurement has been carried out in absolute terms ("What do you see as a person's risk of contracting the flu in Australia this year?"), self-referential terms ("What is *your* risk of contracting the flu this year?") or in comparative terms ("What is your risk of contracting the flu *compared with* other students at your school?"). This comparative assessment relates to the concept of perceived *personal vulnerability / susceptibility* compared with others, in addition to the perceived *general* probability/likelihood of an event occurring and the magnitude of the harm associated with this event (Brewer et al. 2007; Weinstein et al. 2007).

Measuring Risk Perception

There is no universal agreement on how the perception of risk should be measured (Weinstein et al. 2007). Scientists have tended to employ numerical expressions when reporting on risk, including percentages, frequencies and odds ratios. However, there is robust evidence that lay people find verbal scales (using terms such as 'likely' or 'unlikely') easier to use, and experience difficulty in understanding numerical tools (Black et al. 1995; Lipkus et al. 2001). This is not surprising given that most people in everyday life use words rather than numbers to convey perceived risk and uncertainty.

There have been several attempts to evaluate different types of risk perception scales (Weinstein et al. 2007) based on user-friendliness, how well a scale reflects the user's views, intra-rater reliability, internal consistence (tested by comparing ranking based on scale ratings with direct ranking of the hazard

items) and external criteria such as the ability to predict behavioural responses (Diefenbach et al. 1993; Windshitl & Wells 1996; Woloshin et al. 2000). The 7-point and 5-point Likert-type scales (Likert 1932) performed the most effectively on these parameters. In two studies carried out by Diefenbach et al. (1993), subjects rated both the dichotomous (i.e. 2-point) and 9-point scales poorest for accuracy, and low in their choice of scales they liked best. The 2-point scale rated the lowest of all scales examined, for congruence with direct ranking and for intra-rater reliability.

Percentage scales, as tools to measure risk, have been found to present two problems. First, they are rated as difficult to use by participants (Weinstein et al. 2007). Second, there is frequently a distinct spike at 50%, that has been found, after correlations within data sets, to be likely to represent a "Don't know" response, especially if there is not a separate response option for "Don't know" (Fischhoff & De Bruin 1999). Likert-type scales, although rated as easier to use, have a similar problem with potential central tendency bias. This is accentuated if there are an odd number of response options and, therefore, a 'middle option'. Other potential shortcomings with Likert-type scales as a measure of risk perception (and more generally) are acquiescence and social desirability bias. In addition, it cannot be assumed that different response options in Likert-type scales are equidistant. As such, data are ordinal and it has been argued by some authors that non-parametric statistical tools are best employed (discussed further in chapter four). Finally, although individuals tend to be consistent in their interpretation of probability terms such as 'likely', there

are significant inter-individual variations in the interpretations of such terms (Budescu & Wallsten 1985).

In published studies of H1N109 pandemic risk perception (discussed in section 2.5 of this chapter), the principal measures of perceived risk used are Likert-type scales ranging from 3-point to 6-point scales.

Factors affecting the perception of health risk

Despite the different theories and controversies surrounding risk perception, several factors appear consistent in their ability to influence the risk perception concerning health threats. These include perceived control over the illness (Moore & Rosenthal 1996), affective response (Finucane et al. 2000), factual knowledge of the illness, including death as a consequence (De Noouer et al. 2001), knowledge of the disease experience i.e. knowledge of a sufferer (Moore & Rosenthal 1996; Millstein & Halpern-Felsher 2002) and trust in information sources (Slovic 2000; Rubin et al. 2009).

Optimistic bias

In a seminal paper over three and a half decades ago, Weinstein (1980) identified the tendency of individuals to believe that harmful events are more likely to beset other people rather than themselves. He coined the terms 'optimistic bias' and 'unrealistic optimism' to describe this phenomenon. He posited that individuals often view *themselves* as invulnerable, and *other people* as those who are the victims of misfortune. Since 1980 over a hundred

papers have further explored and provided substantive support for his risk perception construct, in a range of different settings (Chapin 2001). Weinstein's own later work in the 1980s (1987, 1989) found that optimistic bias was typically greater for risks perceived to be infrequent events, and over which the person had some degree of perceived control, rather than for uncontrollable hazards. Weinstein and other researchers have offered explanations of why optimistic bias occurs (Weinstein 1984; van der Velde 1992; Hoorens 1994; van der Pligt 1994). There are two main models. The first posits that there is a motivational distortion in the form of unwillingness of individuals to accept vulnerability. Employing this model, optimistic bias could be viewed as a form of defense mechanism employing denial. The second model posits that a cognitive error occurs in the assessment of probabilities whereby the ability of others to mitigate the likelihood of a negative event occurring, is underestimated. Weinstein attributes this underestimation to egocentricity and to stereotyping victims of negative outcomes. He suggests that people egocentrically focus on their own strategies to reduce the likelihood of experiencing an adverse event, but give little thought to the possibility that others may also adopt these same strategies. This cognitive distortion is heightened if the individual holds a stereotypic image of a typical victim that is very different to how the individual perceives himself.

Prentice et al. (2005) explored optimistic bias in the perception of personal risk in people with schizophrenia. In their cross-sectional survey, the authors examined the responses of 25 adults with schizophrenia and 23 controls in the

general population, on their perceived risk of experiencing forty adverse events. The questionnaire divided the negative events into three categories - *controllable*, *uncontrollable* and *neutral*. Adverse events included 'getting the flu' and 'catching pneumonia', which were determined to be in the 'uncontrollable' domain (by nineteen 'healthy controls' in an earlier pilot study). Seven-point Likert scales were used. The degree to which the participants rated the likelihood of themselves experiencing the adverse events as lower than that of others was seen as a measure of optimistic bias. People with schizophrenia were found to demonstrate a lower optimistic bias compared with controls, especially for hazards perceived as controllable, and in this respect may be 'more realistic' in their perception of risk compared with the general population. Specific optimistic bias findings for 'getting the flu' and 'catching a cold' were not published. Psychiatric symptoms as reflected by the Brief Psychiatric Rating Scale and the Scale for the Assessment of Negative Symptoms, had minimal correlation with the ratings of the risk perception questionnaire. These findings are important, and relevant to the thesis research project, as they may impact on how people with schizophrenia perceive the risk of pandemic influenza, and their willingness to undertake a protective action.

In summary

Risk perception is important as it can influence how people behave when exposed to a threat. It is therefore a core component of many health behaviour models. The key dimensions of perception of risk are perceived *likelihood* of a

threat occurring and the *extent of harm* it will cause. The perception of risk has cognitive (risk as analysis) and affective domains (risk as feelings). It is influenced by characteristics such as voluntariness, immediacy, factual knowledge of the threat, familiarity with or past exposure to the threat, associated feelings of fear or dread*,* perceived severity of consequences, perceived level of control over the risk (e.g. vaccination available against pandemic influenza) and level of trust in the information source(s) reporting the threat. Assessment of risk perception involves risk identification and/or risk judgement. Risk judgement can be measured as either a conditional or non-conditional risk. Five-point and seven-point Likert scales are acceptable scales for measuring risk perception. Optimistic bias is an important concept and can influence a person's perception of risk. There is evidence that people with schizophrenia have lower levels of optimistic bias in their risk perception of adverse events, including contracting influenza and pneumonia, compared with people in the general population.

2.5 Pandemic influenza risk perception

Introduction

Research aimed at seeking an understanding of pandemic influenza risk perception (and willingness to adopt protective measures) can be divided into three broad categories. First, there are studies specifically focusing on people's risk perception of a possible future outbreak of avian influenza ('bird flu' / H5N1), which has the potential to be a particularly serious pandemic. The

second category includes the examination of risk perception, and/or willingness to adopt protective behaviours, in the event of a hypothetical future 'generic' influenza pandemic, where the causative viral strain is not specified. Third, there are studies dealing with the most recent influenza pandemic, H1N109, commonly referred to as 'swine flu'.

Although caused by a coronavirus rather than an influenza virus, and therefore not an area of major focus in this thesis, Severe Acute Respiratory Distress Syndrome (SARS) risk perception research has yielded valuable insights into how people respond to a serious outbreak of respiratory disease. It was found that willingness to adopt protective measures was linked to perceived likelihood of oneself contracting the virus, the perceived seriousness of the threat and an individual's level of anxiety about the threat i.e. there were positive correlations between risk perception variables and reported willingness to carry out protective measures (Lau et al. 2003; Leung et al. 2003; Cava et al. 2005).

The studies on avian influenza, SARS and a future 'generic influenza pandemic' were reviewed prior to, and shaped the development of (discussed in chapter four), the thesis research project. The studies pertaining to the H1N109 pandemic were reviewed during and subsequent to the launching of the thesis study, and are included as they provide valuable context for a comparison with the thesis research findings.

Avian influenza (AI)

There have been 11 main studies pertaining to avian influenza risk perception published over the past six years. Eight of these have also explored protective behaviours. Although these studies did not specifically enquire about an avian influenza *pandemic* per se, they are seen as important, because of the potential for H5N1 to result in the next serious pandemic. These studies are summarized in Table 2.5.

Countries involved

The studies have encompassed several different areas of the globe, including Asia, Europe, USA, Africa and the Middle East. Hong Kong was involved in four of the eleven studies. In a large study on both sides of the globe (de Zwart et al. 2007), the authors made a direct comparison between respondents in five European countries (Denmark, The Netherlands, UK, Spain, Poland) and their counterparts in three Asian countries (Singapore, Hong Kong, China).

Study designs and samples

All studies were cross-sectional surveys, including four studies using telephone surveys, three studies using pencil-and-paper questionnaires, three studies using face-to-face interviews, and one large online study. Unlike the other studies, which were single surveys, the web-based study conducted seven cross-sectional surveys over a period of one year, with the aim of exploring trends and temporal relationships between different variables, especially risk perception dimensions and willingness to engage in protective behaviour.

Table 2.5 Studies of Avian Influenza (AI) risk perception

Authors	Country	Sample	Study design	Principal measures	Risk perception	Protective behaviours examined	Findings
Fielding et al. (2005)	Hong Kong	Random sample General population households Aged 16-95 n = 986	Cross sectional telephone survey	Likert scale	Risk perception of AI on exposure to live chicken sales Overall "riskiness to health" Worried about "getting sick" from buying chickens	None	36% perceived buying live chickens as "risky" 9% believed > 50% chance of "getting sick" from buying live chickens 46% said friend had expressed anxiety about AI
Barennes et al. (2007)	Laos	Cluster sample (villages) Random selection of villages and member of house to participate Aged 28-55 n = 1098	Cross sectional survey (face to face)	Structured interview "Standardized questionnaire" (measures not clearly described)	Perceived risk from avian influenza - in Laos generally - at home in context of recent outbreak of AI in poultry in Laos, with first related human deaths in Laos	Stop eating chicken Eat only well-cooked chicken Avoid contact with poultry Stop keeping poultry Wash hands after contact with poultry Wear facemask	Perceived risk from AI: in Laos = 58.2%; at home = 66% Changed behaviour since AI outbreak – Stop eating chicken 37.8% Eat only well cooked chicken 18% Avoid contact with poultry 9.2% Stop keeping poultry 5.3% Wash hands after contact with poultry 2.5% Wear face mask 1.0%
de Zwart et al. (2007)	Denmark, The Netherlands, UK, Spain, Poland, Singapore, Hong Kong China	8 random samples of general population (one in each country) Aged 18-75 n = 3446	Cross sectional telephone survey	1-10 point ordinal scale for perceived severity 1-5 point ordinal scale for perceived vulnerability	Perceived vulnerability, seriousness, response efficacy (of protective measures in general) and self efficacy	Examination of perceived efficacy of protective measures as a whole	45% perceived high or very risk of contracting AI if outbreak occurred in their country Risk perception higher in women and greater age Seriousness = 6.95 (on a 1-10 scale) Response efficacy and self-efficacy inversely associated with risk perception
Lau et al. (2007)	Hong Kong	Random sample Chinese residents in Hong Kong Aged 18-60 n = 503	Cross sectional telephone survey	Likert scale	Risk of outbreak in Hong Kong Risk of self or family contracting AI	Increased hand washing Social isolation Wearing face mask	33% believed there was "high" or "very high" risk of AI outbreak in Hong Kong 53.7% concerned that they or a family member would contract AI if outbreak occurred in Hong Kong 73.8% willing to wear facemask in public venue 92.4% willing to wear facemask if they developed symptoms of influenza 88.3% willing to be socially isolated 86.7% willing to increase frequency of hand washing

Table 2.5 Studies of Avian Influenza (AI) risk perception (continued)

Authors	Country	Sample	Study design	Principal measures	Risk perception	Protective behaviours examined	Findings
Peltz et al. (2007)	Israel	Random sample of 1. General population (n = 500) and 2. Residents of area affected by outbreak of AI in birds (n = 103) Age = 18 or older	Cross sectional telephone survey	Likert scale	Perceived risk of local outbreak becoming a pandemic outbreak	Perceived need for isolation of individuals who become infected with AI	Results very similar in both groups 93-4% "perceived patient isolation necessary" 23-30% perceived risk for pandemic outbreak
Tam et al. (2007)	Hong Kong	Convenience sample of members of local nursing association > 70% below age 45 n = 999	Cross sectional mail questionnaire	Likert scale	Likelihood of outbreak in Hong Kong Afraid of contracting AI Control Accept risk of AI as part of job Consider resigning or changing jobs because of risk of AI	None	49.9% perceived Hong Kong outbreak will occur 72.7% accepted personal risk as part of their work 66.9% of those with low previous exposures to Severe Acute Respiratory Distress Syndrome (SARS) afraid of contracting AI (72.8% of those with high exposure to SARS) 21.9% of those with low exposure to SARS consider resigning of changing jobs because of risk of AI (15.8% of those with high exposure to SARS)
Di Giuseppe et al. (2008)	Italy	Cluster sample of parents of children attending 4 schools Age range – not available (mean age = 40.7) n = 683	Cross sectional survey	Likert scale	Risk of, and seriousness of, contracting AI Ability to avoid contracting AI	None	19.3% felt "very much as risk" of contracting AI 61.9% perceived AI as "serious" 53.3% believed as possible to prevent contracting AI
Gaglia et al. (2008)	USA	Convenience sample of patients attending general medical clinic Aged 18-91 n = 400	Cross sectional survey (pen and paper format)	Likert scale	"Worry" about AI	Vaccination Social isolation Wearing face mask	42% worried about AI 55% willing to undergo vaccination 82% willing to wear facemask 78% willing to be isolated

Table 2.5 Studies of Avian Influenza (AI) risk perception (continued)

Authors	Country	Sample	Study design	Principal measures	Risk perception	Protective behaviours examined	Findings
Aro et al. (2009)	Finnish tourists in Asia (Thailand, Vietnam, China, Malaysia and Singapore)	Random sample drawn from address book of Suntours Aged 20-70 n = 338	Cross sectional survey (pencil and paper)	Structured questionnaire with Likert scales	Own risk of contracting AI Comparative risk (cf same age, gender, country of residence) Perceived control	Avoidance of hand shaking	Own risk of contracting AI: 94.5% low or very low Comparative risk: 46.4% perceived lower or much lower; 47.0% perceived equal Control: 13.5% full control; 81.8% some control Avoidance of hand shaking associated with reduced willingness to take heath risks
Fasina et al. (2009)	Nigeria	Poultry workers in 8 H5N1-affected regions of Nigeria n = 135 Age range – not available	Cross sectional survey – with structured interview	Exact measures used not clear	"Concern" about AI	None	88.6% concerned about AI
Liao et al. (2009)	China	Stratified cluster sampling Random sampling within clusters Aged 20-64 n = 1550	Cross sectional survey (face to face)	Structured interviews and Likert scales	Generalized risk of AI in the region Risk of self or family member contracting AI	Not buying live poultry	55% perceived a "general" risk of AI in the region 18% perceived it likely, very likely or certain that they or a family would contract AI if this occurred Generalized risk but not personal / family risk was associated with choosing not to buy live poultry

Most of the studies of AI employed random samples. However, two studies used a convenience sample, and two studies employed cluster samples. Sample sizes varied from 135 to 3,840. The sampling frames were mostly the general population but some studies targeted specific groups, including poultry workers (Fasina et al. 2009), nurses (Tam et al. 2007), patients attending a general medical clinic (Gaglia et al. 2008), people living in a region of Israel where there had been a local outbreak (Peltz et al. 2007), and Finnish tourists travelling in Asia (Aro et al. 2009).

Principal measures

Likert scales were the principal measures used. However, one study used numerical ordinal scales (1-5, 1-10) calculating mean scores to provide a comparison between participants. Two studies (Barennes et al. 2007; Fasina et al. 2009) were not clear about what measures they used. True/False, Yes/No and open-ended questions were also used. The risk of AI was measured in one study (Tam et al. 2007) by enquiring whether or not the participants (nurses) thought it would lead them to consider resigning or changing jobs. The study of a Laotian population measured participants' perceived risk of contracting AI both in the local area as well as in Laos generally.

Risk perception variables evaluated

Collectively, the risk perception variables explored in these studies included:

1. Perceived risk associated with buying live chickens (Hong Kong)

2. Perceived likelihood of outbreak in own country / local area

3. Perceived likelihood of self or family member contracting AI

4. Perceived likelihood of self contracting AI compared with someone of the same age, gender and country of residence

5. Perceived severity of contracting AI

6. Perceived control over avoiding contracting AI

Protective measures evaluated

Collectively, the studies of AI evaluated the following protective measures:

1. Vaccination

2. Increased hand washing

3. Wearing a face mask

4. Isolation / social distancing

5. Avoiding hand shaking

6. Not eating poultry

7. Eating only well-cooked chickens

8. Not keeping poultry

9. Not travelling to areas of AI outbreaks

Findings

Overall these studies were reasonably consistent with one another, indicating that a significant proportion of people perceived their own risk of contracting AI during a local outbreak as substantial, and perceived it as a serious situation if they did. Lau et al. (2007) found that 53.7% of participants were concerned

that they themselves, or a family member, would contact AI if it occurred in their country (Hong Kong). Similarly, de Zwart et al. (2007) found 45% of those surveyed perceived a high or very high risk of becoming infected if an outbreak of AI occurred in their country and the mean seriousness rating was 6.95 on a 1-10 numerical scale. In an Italian study (Di Giuseppe et al. 2008), 61.9% of participants perceived AI as serious. Interestingly, the study of European tourists in Asia (Aro et al. 2009) yielded different findings for perceived personal risk, with 94.5% of respondents indicating that they perceived a low or very low risk of contracting AI. However, a methodological shortcoming of this study was that it did not specify whether or not the travel period in question was during a known outbreak of AI.

The Asian studies suggest that respondents perceived a relatively high perceived risk of an outbreak occurring at some time in their country. The US study (Gaglia et al. 2008) found the proportion of participants concerned about AI in general (42%) was lower than that found in the Nigerian study (88.6%) (Fasina et al. 2009). This is not surprising given that the population samples were very different (attendees of a medical clinic in the US versus poultry workers in Nigeria), highlighting one of the difficulties in making comparisons between the studies. Direct comparison of risk perceptions between studies was sometimes also complicated by the different ways in which risk and willingness to undertake (or reported *actual* undertaking of) protective behaviors, was measured. Even though Likert scales were widely used, the wording of the questionnaire or interview items was different. In addition, some

questionnaires enquired about perceived risk in an indirect or general way (e.g. worry about AI, concern about AI, or perceived risk from AI), without specifically exploring perceived *likelihood* and perceived *severity* dimensions of risk.

There was generally a high willingness to adopt protective measures during an AI outbreak. For instance, Lau et al. (2007) found that 86.7% of the sample of Chinese residents in Hong Kong were willing to increase hand washing, 73.8% were willing to wear a face mask in a public venue, and 88.3% were willing to be isolated in the event of an outbreak of AI in their country. Similarly, Gaglia et al. (2008) found that 82% of adults attending a general medical clinic in the US were willing to wear a face mask, 78% were willing to be isolated, and 55% were willing to receive a vaccination. In the Israeli study (Peltz et al. 2007) 93-94% of respondents viewed isolation as necessary if AI were contracted in their country.

Future 'generic' pandemic influenza

There was only one study examining risk perceptions of, and willingness to adopt precautionary measures against, a hypothetical generic pandemic influenza (Barr et al. 2008). The sampling frame in this study was the general population of New South Wales (NSW), in Australia. A module of questions was formulated and field-tested on 192 adults in NSW using Computer Assisted Telephone Interviewing (CATI). The questions were subsequently modified with further field testing of 202 adults. The adjusted module of

questions was then incorporated into the NSW population survey in early 2007. A representative sample consisting of 2,081 adults completed the module of questions and their responses were weighted against the general population of NSW. While only 14.9% of participants perceived pandemic influenza as very or extremely likely to occur, 45.5% were very or extremely concerned that they themselves or a family member would be 'directly affected' by the pandemic. About a quarter of respondents indicated that they had made some change to the way they lived their lives because of the possibility of pandemic influenza. The majority was willing to be vaccinated (75.4%), self-isolate (70.2%) and wear a face mask (59.9%). These baseline data have value in enabling the monitoring of changes over time in this population's perceptions of risk associated with pandemic influenza and willingness to adhere to recommended protective health behaviours.

H1N109 pandemic influenza

At the time of writing, the H1N109 influenza pandemic is the most recent serious influenza outbreak and is the focus of the thesis research project. The cross-sectional survey in the present study took place over a four-month period, starting three weeks after the World Health Organization declared the H1N109 influenza outbreak a global pandemic, and two months after the first 'case' was identified (and laboratory-confirmed) in Australia. At the time of writing there have been 11 published (English language) studies examining risk perception of H1N109 and all bar one of these have also explored

associated protective behaviours. These studies are summarized in Table 2.6 and discussed below.

Countries involved

The studies involved different populations from around the world – Hong Kong, USA, Britain, Australia and Turkey. Hong Kong was particularly well represented. This is likely to be related to it bearing the brunt of the SARS epidemic as well as suffering mortalities from avian influenza.

Study designs and samples

Ten of the studies were cross sectional surveys, comprising four telephone surveys, four pencil-and-paper surveys, and two surveys conducted online. One study (Gargano et al. 2011) was longitudinal, conducting a pre-winter (northern hemisphere) baseline, with post-winter follow-up, to determine the proportion of respondents with a reported intent to have a vaccination who actually did receive one. A large cross-sectional study (n = 12,965) surveyed its sample population on 13 occasions over a 9 month period to explore trends and changes in variables over time (Cowling et al. 2010). Most studies recruited a random sample but some were methodologically less sound, employing convenience samples and cluster samples, rendering their findings less able to be generalized. The sample sizes varied considerably, ranging from 66 to almost 13,000. In all the studies, participants were adults (i.e. aged 18 or over). Although the sample frame for most of the studies was the general

Table 2.6 Studies of H1N109 ('swine flu') risk perception

Authors	Country	Sample	Study design	Principal measures	Risk perceptions	Protective behaviours examined	Findings
Chor et al. (2009)	Hong Kong	Convenience sample Public hospital healthcare workers Age range –not available n = 2255	Cross sectional survey (pen and paper)	Likert scales	Likelihood of being infected	Vaccination	47.9% willingness to accept vaccination Predictors were perceived risk of contracting infection and history of seasonal flu vaccination No data reported on risk perception per se
Jones & Salathe (2009)	Predominantly USA (69%)	Self-selected sample of those with access to an online computer Aged 18-93 n = 6,249	Online Cross sectional survey	9-point ordinal scale with "anchors" at the extremes ("very low" and "very high")	Overall perceived risk from H1N109 (comparisons made with other health threats such as heart disease and cancer) Perceived likelihood of self contracting H1N109 Self-reported anxiety levels	Social distancing Hand washing Face mask	Mean perceived threat was 3 on a scale 1-5, higher than perceived threat from heart disease and cancer but perceived personal risk of contracting H1N1 was low with about 50% of respondents reporting a score of 1 or 2 (1= highly unlikely, 9 = highly likely); perceptions of being able to avoid infection were high. Risk perception and anxiety levels waned over time. Association present between anxiety levels and willingness to engage in protective behaviours
Lau et al. (2009)	Hong Kong	Random sample of Chinese Hong Kong residents Aged 18-60 n = 550	Cross sectional telephone survey	Structured questionnaire (exact measures not reported)	Likelihood of outbreak in local area Risk of catching illness (self or family member) Severity of illness	Facemask Hand washing Social isolation	Overall H1N1 was "not perceived as threatening" 22.1% perceived likely local outbreak Perception of high or very high risk of catching H1N1 – 7.5% for self, 8.4% for family and 12.2% for general public Only 21.5% believed it would be seriously physically threatening if they contracted it 73.6% were carrying out frequent hand washing with 97.6% believing this was effective 47.9% reported willingness to wear a facemask in public venue if they developed flu-like symptoms 93.3% perceived regular use of facemask as efficacious
Rubin et al. (2009)	England, Scotland and Wales	Random sample of general population Aged 18 or over n = 997	Cross sectional telephone survey	Likert scales State Trait Anxiety Inventory	Risk of catching infection Severity of illness Ability to avoid catching virus (control)	Hand washing Social isolation	Intermediate risk perception of likelihood (2.3 on scale of 1-5) and severity (2.8 on scale of 1-5); high perception of control (4.0 on scale of 1-5). Predictors of willingness to carry out protective behaviours were perceived likelihood to catch infection, its severity, duration of outbreak and perceived efficacy of precautionary measure

Table 2.6 Studies of H1N109 ('swine flu') risk perception (continued)

Authors	Country	Sample	Study design	Principal measures	Risk perceptions (RP)	Protective behaviours examined	Findings
Akan et al. (2010)	Turkey	First year university students Systematic sampling (1in every 4 student enrollment approached) Age range – not available n = 402	Cross sectional survey (pencil and paper)	Likert scales, Multiple Choice Questions (MCQs), and open ended questions	Likelihood of self becoming infected	Vaccination Social isolation Face mask Hand washing	Perceived likelihood of self contracting H1N109: 25.1% high; 40.5% moderate; 20.6% low; 92.8% not willing to be vaccinated (concerns about safety and side effects) Vast majority believed hand washing, social distancing and face mask were effective
Cowling et al. (2010)	Hong Kong	Random sample of Hong Kong residents Aged 18 or older Aged ≥ 20 n = 12,965	13 cross sectional telephone surveys over 9 month period	Likert scales State Trait Anxiety Inventory Self-rated general health	Own susceptibility Worry if developed influenza-like illness (ILI) Severity compared with Severe Respiratory Distress Syndrome (SARS)	Hand washing Facemask Social distancing	Perceived susceptibility and severity "high" and then declined over time Low anxiety levels throughout Hand washing and facemask use did not change over time but social distancing declined Higher anxiety associated with lower use of hand washing but greater social distancing Female gender and higher level of education, knowledge about viral transmission - associated with more used of hand hygiene Use of face mask associated with poorer self rated health, higher perceived risk of infection and greater worry if ILI developed
Eastwood et al. (2010)	Australia	Random sample of general population Aged 18 or older n = 830	Cross sectional Telephone survey	Structured interview Likert scale MCQ Opened ended questions	Severity Likelihood of self or family becoming infected	Increased hand washing Facemask	77.7% reported H1N109 as mild 77.8% reported being not or only a little concerned about self or family becoming infected 46.6% reported increased hand washing 8.7% had purchased a facemask 6.0% had worn a facemask in public 77.8% reported low anxiety

Table 2.6 Studies of H1N109 ('swine flu') risk perception (continued)

Authors	Country	Sample	Study design	Principal measures	Risk perceptions	Protective behaviours examined	Findings
Ibuka et al. (2010)	USA	General adult population Aged 18 or older n = 1290	Online cross sectional survey	Numerical scales (11-point for perceived likelihood and 5 options for severity)	Perceived likelihood of H1N1 occurring in local area + own risk of exposure to it (combined into single "perceived likelihood" scale-high Cronbach α) Severity measured by asking how many people will die world wide	Willingness to (1) receive and (2) pay for vaccination and / or antiviral medication Willingness for social distancing	"Perceived likelihood" increased over time but interest in vaccination/antivirals and engagement in precautionary activities decreased over time Higher perceived likelihood of infection if lived in region with higher incidence of H1N109 per population but not a greater interest in vaccine or antivirals or of engagement in precautionary measures "Perceived likelihood" and willingness to pay for vaccination or antiviral medication - higher in women
Seale et al. (2010)	Australia	Convenience sample of adults in shopping malls in Sydney Aged ≥18 n = 627	Cross sectional intercept survey	Likert scales	Own risk of infection Average Sydney resident's risk of infection Seriousness Control	Vaccination Social distancing Hand washing	Perceived likelihood of self becoming infected - 52.9% reported low-very low Perceived likelihood of "average Sydney resident" becoming infected - 43.4% reported low-very low 24.5% - perceived it would very or extremely seriously affect their own health 48.3% increased hand washing Low level of social distancing 52.5% willing to vaccination if government health authorities recommend it (71.5% if own doctor recommended it)
Wong et al. (2010)	Hong Kong	Convenience Cluster sample of School teachers n = 1169	Cross sectional survey	Likert scales	Worries about the spread of H1N1 and "psychological reaction" (not clear exactly what this denotes)	None	"Moderate" levels of worry about the spread of H1N1 but low psychological reaction
Gargano et al. (2011)	USA	Convenience sample of school teachers and staff Aged 24-68 n = 66	Longitudinal study (pencil and paper) Baseline and follow-up 8mths later	Likert scales	Perceived susceptibility Seriousness	Vaccination	78% of those intending to have seasonal flu vaccine reported they did so 36% of those intending to have H1N109 vaccine did so Uptake of H1N109 vaccine associated with perceived barriers (esp. concern about side effects and having a "new" vaccine)

population, some targeted specific groups. These included public hospital health care workers (Chor et al. 2009), university students (Akan et al. 2010), and school teachers (Wong et al. 2010; Gargano et al. 2011). Although the online studies (Jones & Salathe 2009; Ibuka et al. 2010) surveyed general population samples, it needs to be acknowledged that the sampling frame in these studies is restricted to those people having access to an online computer, resulting in a clear self-selection bias. Therefore, these studies are less likely to obtain the responses of people suffering from social impoverishment, which includes many people with a serious mental illness such as schizophrenia. The online studies may also have been subjected to bias associated with age, gender, level of education and cultural background, affecting access to, and attitudes towards, computers and web-based surveys. Finally, a source of self-selection bias inherent in the online surveys is that those people with more interest in, or anxiety related to, H1N109, are more likely to have responded.

Principal measures

Most of the studies used Likert-type scales (ranging from 3-point to 6-point scales) as the principal measures. Multiple choice questions, binary Yes/No questions and open-ended questions within structured interviews were also employed. Two studies (Ibuka et al. 2010; Jones & Salathe 2009) used numerical scales with anchor points at the upper and lower ends ("Very low" and "Very high"). A weakness of a minority of the studies was a failure to adequately define some of the measures used. For instance, in the Hong Kong

study of school teachers (Wong et al. 2010), the term "psychological reaction" as a risk perception of H1N109 was used without a clear explanation of what this denoted and what precisely was being measured.

Risk perception variables evaluated

Collectively, the risk perception variables explored in these studies included:

1. Perceived likelihood of an outbreak of swine flu occurring in the respondents' local area

2. Perceived likelihood of oneself contracting swine flu

3. Perceived likelihood of a family member contracting swine flu

4. Perceived likelihood of another adult in the same region contracting swine flu

5. Presence and/or level of worry about swine flu or developing an influenza-like illness (ILI)

6. Perceived seriousness of contracting swine flu (this was mostly explored in the sense of perceived serious harm to oneself, but in one study it was measured by asking how many people world-wide would die from it)

7. Perceived control i.e. the perception of one's ability to avoid contracting swine flu

Protective measures evaluated

Collectively the studies examined the following protective measures:

1. Vaccination

2. Anti-viral medication (as a prophylaxis)

3. Increased hand washing

4. Social isolation

5. Wearing a face mask

6. Increased cleaning (e.g. with a disinfectant solution) of objects touched often, such as a door knob

Although most of the studies were general in their enquiries about increased hand washing, some were quite specific, such as evaluating whether soap and water were used, or whether alcoholic gel was used (Seale et al. 2010). Similarly, with social isolation / distancing, a minority of studies were very specific with items on their questionnaire, evaluating: reduced use of public transport; keeping children out of school; avoiding doctors' surgeries; reduced visits to shops; and cancelling social events such as eating out or going to a sporting event.

Findings

Comparison of results from different studies is complicated by the following:

1. Studies were conducted at different stages of a rapidly evolving event with varying information being delivered from both the media and health officials at different stages of the pandemic.

2. Some studies had specific groups, rather than the general population, as their sampling frame (as discussed above).

3. Different measures were used.

4. Convenience samples used in some studies make it difficult to generalize findings.

However, taken as a body of research, the findings suggest that most people perceived a low to moderate level of threat from the H1N109 outbreak, both in terms of *likelihood* of themselves or a family member contracting the virus, and also in terms of it being *serious* if they did. For instance, in the Eastwood et al. (2010) study, 77.8% of participants reported H1N109 as "mild" in terms of severity and 77.8% reported being not, or only a little, concerned about themselves or a family member becoming infected with the virus. There was also evidence of a high degree of willingness to undergo protective measures, including vaccination as well as infection control measures (hand washing, wearing a mask and social isolation). The exception to this was the study of the Turkish population of first year university students (Akan et al. 2010) where 92% were *not* willing to be vaccinated, mainly due to reported concerns about safety and side effects.

Many of H1N109 risk perception studies revealed a positive correlation between risk perception variables and willingness to adopt protective measures. Both *perceived seriousness* of H1N109 (Rubin et al. 2009; Chor et al. 2009; Lau et al. 2010; Setbon & Raude 2010) and *perceived likelihood* of contracting H1N109 (Rubin et al. 2009; Chor et al. 2009; Lau et al. 2010) were demonstrated to be significant predictors of willingness to carry out preventative actions. There was also evidence for a correlation between self-reported anxiety levels (9-point ordinal scale, ranging from very calm to very anxious) and willingness to engage in protective behaviours, in adults in an online survey (Jones & Salathe 2009). There were conflicting findings in terms

of changes in risk perception over time. Jones & Salathe (2009) found that *'overall perceived risk'* (*perceived likelihood* and *perceived severity* not measured), and anxiety levels, decreased over time, whereas Ibuka et al. (2010) found a slight increase in *perceived likelihood* of exposure to a person infected with swine flu (and therefore one's risk of contracting the virus), over time. Both of these studies were based in the US with their surveys commencing on 28 April 2009 i.e. early in the pandemic.

In summary

Risk perception (both *perceived likelihood* of becoming infected, and *perceived seriousness*) of the 2009 swine influenza outbreak was generally lower than that found in the studies on avian influenza pandemic risk perception. This may have been due to public messaging by health authorities communicating the relatively low case fatality rate of the H1N109 virus, in contrast to the high human lethality of 'bird flu'. However, self-reported willingness to undergo protective measures was substantial for both H1N109 and H5N1 threats, as it was for the study evaluating response to a hypothetical 'generic' influenza pandemic in Australia (Barr et al. 2008). There was evidence of an association between risk perception (*perceived likelihood* of contracting the virus and *perceived seriousness*) and reported *willingness* to carry out protective measures in many studies, as was found with SARS.

2.6 Protective behaviours in a pandemic influenza

As mentioned earlier, the adoption of protective interventions is a core component of any effective response plan to mitigate the negative outcomes associated with an influenza pandemic. Vaccination and infection control measures (increased hand washing, social isolation and wearing a face mask) are discussed.

Vaccination

Modelling has indicated that vaccination could significantly reduce the number of people infected during a pandemic influenza, as well as hospitalization rates and mortality rates (Nuno et al. 2007). However, there are likely to be delays in the development of an effective vaccine during an influenza pandemic as well as limitations in supply. With respect to the H1N109 outbreak, the specific vaccine against the novel virus was not available until 30 September 2009. The outbreak, globally, began in late March 2009 (i.e. six months earlier).

Killed influenza vaccines vary in their effectiveness from year to year for seasonal influenza, depending on the virulence of the prevailing viruses and the 'match' between these circulating viruses and the available vaccine. There is also variation in vaccine effectiveness related to the age of the patient and whether he/she is in a high risk group (e.g. co-existing heart disease, diabetes mellitus, chronic obstructive airways disease and other respiratory disorders, immune deficiency, indigenous cultural background, and pregnancy). Influenza vaccines are most effective in healthy young adults and older children and

least effective for children under the age of two and adults older than 65 (Centres for Disease Control and Prevention 2011). In the presence of a favourable match between circulating influenza strains and those in the vaccine, influenza vaccination can prevent illness in 70-90% of healthy individuals (National Centre for Immunisation Research & Surveillance 2011). Although most people may benefit from influenza vaccination, it is especially important for people in vulnerable groups, including people with schizophrenia, during an influenza pandemic.

Infection control protective measures (hand washing, face mask and social isolation)

A recent Cochrane Review (Jefferson et al. 2008) examined a range of randomized controlled trials (RCTs), cohort, case-control, cross-over and time series studies regarding the effectiveness of hand hygiene, self isolation/social distancing and wearing surgical face masks to interrupt or reduce the spread of respiratory viruses. A variety of settings were evaluated, including suburban schools, military barracks, paediatric wards, and day-care centres. The review concluded that these simple infection control measures are highly effective in reducing the transmission of respiratory viruses. In a follow-up systematic review two years later (Jefferson at al. 2010), the authors found similar results. However, they identified poor compliance as a leading problem with these infection control interventions, especially when the health threat is perceived to be low. The authors asserted that the most important barrier to implementation of infection control measures is behavioural change. A key study supporting

the effectiveness of hand washing against an influenza H1N1 virus was conducted by Grayson et al. (2009). Twenty vaccinated healthcare workers had their hands contaminated with 1ml of an infectious dose of tissue cultured live human influenza A/New Caledonia/20/99 before carrying out various hand hygiene protocols including: (1) soap and water, (ii) 61.5% ethanol gel, (iii) 70% ethanol gel + chlorhexidine 0.5% solution, (iv) 70% isopropanol + chlorhexidine 0.5% solution, and (v) no hand hygiene (control). Concentrations of the H1N1 virus on participants' hands were measured before and after each intervention, by viral tissue culture and real-time polymerase chain reaction (PCR). All four active hand hygiene interventions showed highly successful antiviral activity, with 14 out of 14 participants having no culturable H1N1 virus. PCR results also showed both soap and water as well as the three alcohol-based hand rubs to be highly effective in reducing influenza A on volunteers' hands. There was minimal change in the H1N1 concentration after one hour on the hands of participants who were in the control group. The authors concluded that hand hygiene was a potentially important public health measure to reduce viral transmission during a pandemic, and also for avian influenza.

There has been a recent initiative in Australia to improve the standards of hand hygiene, principally in health care workers but also in the Australian community more broadly. The Australian Commission on Quality and Safety in Health Care (ACQSHC) has launched a national campaign called the National Hand Hygiene Initiative (NHHI). Its objectives include improving compliance rates of hand hygiene in healthcare workers, reducing rates of health care associated

infection (HCAI), developing an effective education and credentialing system for knowledge and skills of hand hygiene and infection control, and to place hand hygiene as a core issue for all healthcare institutions and the wider Australian community (Hand Hygiene Australia 2013). To promote improved hand hygiene the campaign utilizes resources such as workshops, online learning packages, information brochures (available online), fact sheets and posters, useful Internet links and FAQs (frequently asked questions) answer sheets.

During the SARS outbreak in Hong Kong, laboratory-confirmed respiratory viral infection rates in the general population decreased by over 80% when the general population carried out strategies of increased hand hygiene, social isolation / distancing, and wearing a face mask (Lo et al. 2005; Collignon & Carnie 2006).

A systematic review conducted by Aledort et al. (2007) evaluated the evidence base supporting the use of 'non-pharmaceutical' (i.e. infection control) public health interventions *during a pandemic influenza*. The authors examined papers between 1966 and 2005, as well as convening meetings with experts in various medical disciplines, to elicit expert opinion. The studies evaluated included: nine systematic reviews, three RCTs, twenty-nine observational studies (including case-control and prospective studies), twelve mathematical / epidemiological modeling studies, thirty case reports / case series, nine evidence based guidelines, twenty-seven expert opinions and forty-nine

narrative studies (summary by an expert citing references obtained in a non-systematic manner). The authors concluded that the literature contained a dearth of higher level evidence for the efficacy or effectiveness of non-pharmaceutical infection control measures *during a pandemic*, and that policy recommendations must rely principally on expert opinion. Expert judgement endorsed increased hand washing, the use of face masks by infected individuals and their carers, and self-isolation by infected people during all phases of a pandemic influenza. Use of face masks by non-infected members of the general public, school and workplace closures, and mandatory travel restrictions were not recommended, as they were viewed as likely to be ineffective and unacceptable to the general public.

With respect to the H1N109 pandemic, the Centres for Disease Control and Prevention (CDC) recommended and endorsed all three infection control measures (i.e. self isolation, wearing a face mask and hand washing). However, face mask was recommended only for those who were in a vulnerable (i.e. high risk) group and could not avoid a crowded community setting, and for vulnerable care-givers to an individual infected with H1N109. Although face masks decrease the quantity of virus-laden droplets inhaled or deposited on mucous membranes, their principal mode of efficacy may be reducing the ability of a person exposed to a respiratory virus to directly touch their nose or mouth, and thereby reduce self-innoculation (Collignon & Carnie 2006).

Perceived barriers to adopting protective measures

Vaccination

There have been numerous studies examining perceived barriers to receiving a vaccination (Kaufman et al. 2008; Maltezou et al. 2008; Askarian et al. 2009; Shroufi et al. 2009; Akan et al. 2010; Seale et al. 2010; Feemster et al. 2011). Two of these (Akan et al. 2010; Seale et al. 2010) relate specifically to the H1N109 pandemic influenza and the remainder to seasonal influenza. Seale et al. (2010) carried out a cross-sectional survey of Sydney residents using a convenience sample (n = 627), in September / October 2009. Although most participants did not believe they were at high risk of contracting H1N109, more than half (54.7%) indicated they would be willing to receive the vaccine. The principal reasons given by participants for not accepting the H1N109 vaccination identified in this study were: (1) "the situation is not serious enough" (31%); (2) "not at risk" (18%); (3) "concerns" about the H1N1 vaccine (16%); (4) belief in one's own health or immune system (12%); (5) concern about vaccinations in general (7%); (6) "need more information" (7%); (7) concerns about annual influenza vaccination (4%); and (8) "already exposed" (4%). It was also found that those who had received a previous vaccination against seasonal influenza were more likely to accept an H1N109 vaccine.

In contrast to these findings, a Turkish cross-sectional survey of 402 first year university students (Akan et al. 2010), found that 92% of participants indicated they would not accept a vaccine against H1N109. However, this study was conducted in November 2009, and therefore after the peak of the outbreak in

northern hemisphere countries. The chief barriers cited were: (1) "it is not safe" (26.4%); (2) "I don't trust it" (21.3%); (3) "I don't need it since I am not in a risk group" (15.3%); (4) "ineffective" (7.5%); (5) "it is too late, I will wait for the vaccines produced in the USA" (4.2%); and (6) "I don't want to be a guinea pig" (2.2%). Studies exploring reasons for refusal of seasonal influenza vaccinations have found similar barriers. For instance, a large cross-sectional study (n = 8062) of health care workers in nationwide Greece (Maltezou et al. 2008) found that the principal reasons for declining an influenza vaccine were the belief of not being at risk of contracting influenza (43.2%) and fear of side effects (33.4%).

Social isolation

There has been considerably less research exploring perceived barriers for social isolation. In the Seale et al. (2010) study of Sydney residents described above, most participants indicated that they would experience "home quarantine" (i.e. recommended isolation at home) as highly or very highly inconvenient, or a problem. The principal difficulties associated with self-isolation at home were identified as "not being able to attend work" (52.4%) and "not having access to groceries and other supplies" (40.2%). Those who were self-employed or in casual employment were 50% more likely to rate "not being able to work" as problematic. Age was a predictor for identifying "not having access to groceries and other supplies" as problematic with respect to home isolation. Participants under the age of 35 were close to 50% more likely than those above this age to see these factors as problematic.

A study of the general population of the US (n = 1697) using random digit dialing, explored perceived barriers for complying with pandemic influenza mitigation strategies, including staying away from work for at least 7-10 days (Blake et al. 2010). It revealed that the chief concerns among respondents about not going into work, related to fear of losing their job and experiencing severe financial problems.

Hand washing

Despite hand washing being a simple and effective infection control measure (Jefferson et al. 2010) compliance with hand hygiene protocols, even among qualified health care workers, is poor, with evidence of levels of 50 – 60% at best (De Wandel et al. 2010). No studies specifically examining perceived barriers to hand washing *during a pandemic influenza* were identified at the time of writing. However, there have been multiple studies carried out in other contexts, mostly among health care staff at their work place, with a consistency of findings. Common perceived barriers for hand washing in these studies are: (1) limited or no access to facilities (e.g. sinks); (2) time and "busyness"; (3) skin irritation; and (4) lack of outcome expectancy (Pittet 2001; Larson 2004; Barret & Randle 2007; Nazarko 2009; Bolon M 2011; Helms et al. 2010).

Face mask

The term 'face mask' usually refers to soft, disposable face masks, sometimes also referred to as 'surgical face mask', 'dental face mask', 'medical procedure

face mask' or 'isolation face mask'. When used by the CDC, the term 'facemask' refers to disposable face masks that have been 'cleared' by the US Food and Drug Administration as a medical device (Centres for Disease Control and Prevention 2009). There exist two uses for such face masks. First, they may be used by individuals who currently do not have any symptoms of respiratory infection, as a preventative measure to avoid contracting the infection. Second, they may be used by individuals who are infected with a respiratory pathogen, in order to reduce the risk of spread to others. There are several designs, which are all reasonably similar. In one design, the mask, which may be flat or duck-billed in shape, is affixed to the head with two ties and has a flexible adjustment for the nose bridge. In another design, the mask is pre-molded and attaches to the wearer's head with a single elastic strap, also having an adjustment for the nose bridge. In a third design, the body of the mask is flat, and ear loops are used to affix the mask to the head. All designs of face mask that have been approved by the FDA for use as 'medical devices', have been assessed to provide specific levels of protection against penetration of droplets of body fluids. Although they do not prevent inhalation of very small particles potentially containing the virus, they do help protect against droplets and splashes or sprays spreading from one individual to another (Centres for Disease Control and Prevention 2009).

Relatively little research has been published exploring perceived barriers to wearing a mask as a protective measure against contracting influenza. However, a useful prospective randomized trial was conducted by MacIntyre et

al. (2009), examining the effectiveness of face masks in preventing the spread of influenza-like illness in Australian households. It included self-reported barriers to wearing a face mask, which were worn by both the infected person and by the non-infected primary care-giver. Approximately 50% of respondents indicated concerns related to this protective measure. The most commonly reported barrier (17% of participants) was discomfort associated with wearing a face mask. Additional barriers included: (1) forgetting to wear it (9%); (2) the respondent's child / children did not like it (8%); and (3) "other" (19%), which included the mask not fitting properly and it being inconvenient to wear during meal times or when asleep. In a US study of an urban Hispanic population (Ferng et al. 2011), qualitative data were obtained at home visits and through a focus group, to explore barriers to wearing a face mask to protect against contracting influenza-like illnesses present in households. The face mask in this study was only worn by non-infected individuals. Similar to the MacIntrye et al. (2009) study, comfort and fit were reported barriers, but other thematic barriers identified included social acceptability of mask use and participants' *perception of the risk* related to the respiratory infection and whether they thought a mask was needed.

In summary

Vaccination and infection control measures are important in mitigating the negative impact of a pandemic influenza. Although vaccination has been shown to significantly reduce the number of people infected, and hospitalization and mortality rates during a pandemic influenza, limitations in

supply and effectiveness are likely to be an issue. Increased hand washing, social isolation and wearing a face mask have been shown to be effective in the reducing the transmission of respiratory viruses (Jefferson et al. 2008, 2010) but poor adherence may place restrictions on their usefulness in a pandemic (Jefferson et al. 2008). Therefore, knowledge of perceived barriers to protective measures is highly relevant in planning for a pandemic, in order to facilitate their implementation.

2.7 Conclusion

As pandemic influenzas are recurring and continually evolving health threats, there is a need to monitor for their emergence and to have an effective response plan. Pandemic influenza remains a serious threat in the 21st century, especially with the possibility of a highly virulent strain of avian influenza (H5N1) developing the capacity for human-to-human transmission, which would enable it to potentially result in millions of deaths world-wide. It is important during a pandemic for the public, especially vulnerable groups such as people with schizophrenia, to have access to relevant, up-to-date and accurate health information, in order to know what to do in the circumstances of a pandemic. This information would include notification of the emergence of the pandemic virus, how serious it is, and what protective measures a person may need to take. There is currently a dearth of research and understanding of how people with schizophrenia acquire health information. A core aim of this study is to evaluate how much health information people with schizophrenia

acquire from various sources and the level of trust they invest in those sources. The range of health information sources now enable the general public to take an active role in managing their own health, and it is important that people with schizophrenia have equity with respect to these opportunities. Many advances have occurred in the field of risk perception in recent decades. An understanding of people's perception of risk associated with a pandemic influenza is important because risk perception variables have been found to be key predictors of willingness to undertake preventative actions. Vaccination, hand washing, social isolation and wearing a face mask have been shown to be important protective measures by reducing viral transmission, resulting in benefits both for the individual and the community as a whole. An understanding of what people see as difficult or challenging about carrying out a given protective measure is of value, as perceived barriers influence uptake of preventative measures. There is currently no research exploring the risk perceptions of people with schizophrenia with respect to a pandemic influenza. This is important given their particular vulnerability to complications and death as a result of influenza infection. There is also an absence of research evaluating their willingness to adopt protective measures during an influenza pandemic and what they perceive as barriers to carrying out these protective actions. There is a pressing need to fill these gaps in the literature to enhance preparedness and response planning for this vulnerable group in order to mitigate the negative impact of a future, possibly highly virulent, influenza outbreak.

CHAPTER THREE

RATIONALE FOR THE THESIS RESEARCH PROJECT

3.1 Introduction

This chapter describes the rationale for the thesis research project, including the heightened risks associated with pandemic influenza for people with schizophrenia, gaps in current knowledge base, research aims, research questions and research hypotheses.

3.2 Heightened risk during pandemic influenza for people with schizophrenia

As established in chapter one, there are heightened risks for people with schizophrenia to influenza, especially in the event of a pandemic influenza. These may be summarized as follows:

1. A very large (n = 231,311) Australian study (Lawrence et al. 2001) has shown:

(i) People using mental health services, including people with schizophrenia, have considerably higher mortality rates from *influenza and pneumonia* than those in the general population (5.4 times higher for men; 3.4 times higher for women).

(ii) People using mental health services, including people with schizophrenia, have over 50% excess risk for hospitalization for influenza, compared with those in the general population (42% increased risk for men; 65% increased risk for women).

(iii) Men with schizophrenia have 2.5 times higher mortality rates from *influenza and pneumonia* compared with men in the general population.

(iv) Men with schizophrenia have 35% higher hospitalization rates for influenza than men in the general population.

(v) Men and women with schizophrenia have increased hospitalization rates for pneumonia compared with the general population (1.23 times higher for men; 1.19 times higher for women). Pneumonia is a recognized complication of influenza, and, therefore, these increased rates also reflect vulnerability during an influenza pandemic.

2. People with schizophrenia are 2.5-3.0 times more likely to be smokers (65-92% are smokers), and to smoke more heavily, than people in the general population (Connolly & Kelly 2005; Levander et al. 2007; von Hausswolff-Juhlin et al. 2009; Morgan et al. 2012). Smokers have been shown to have approximately double the rate of influenza, tend to have more severe influenza infections, have higher mortality rates from influenza, and are more likely to

have a background of chronic obstructive pulmonary disease, compared with non-smokers (Murin & Bilello 2005).

3. Alcohol use disorders are a common comorbidity in people with schizophrenia and are significantly more prevalent than in the general population, as discussed in chapter one (Regier et al.1990; McCreadie, Scottish Comorbidity Study Group 2003; Gregg et al. 2007; Koskinen et al. 2009). Pulmonary infections, especially pneumonia, are more common and more severe in people who misuse alcohol, tending to be characterized by frequent complications and poor outcomes (Zhang et al. 2008).

4. Obesity, a frequent side effect of antipsychotic medication, is a risk factor for both the development of respiratory infections as well as for poor outcomes from influenza and pneumonia (Murugan & Sharma 2008).

5. People with schizophrenia have poorer access to primary health care, receive poorer quality of care, and are less adherent to general medical treatment compared with the general population (Brown et al. 2000; Druss et al. 2001; Lambert et al. 2003; Kohn et al. 2004; Nasrallah et al. 2006; Newcomer & Hennekens 2007).

6. People with schizophrenia have increased rates of serious medical disorders such as chronic obstructive airways disease, ischaemic heart disease and diabetes mellitus type II (Jablensky et al. 2011). These disorders

are associated with increased likelihood of complications and mortality in the event of contracting influenza (Centres for Disease Control and Prevention 2009).

3.3 Gaps in the current state of knowledge

(1) Using and trusting health information sources is an essential aspect of dealing with health threats. Given their high rates of medical comorbidity and mortality discussed in chapter one, people with schizophrenia need to be able to receive evidence-based, and appropriately communicated, health information. As discussed in chapter two, it is important during a pandemic influenza to be able to access accurate and timely information updating the current situation and providing recommendations. It is also important to be able to trust the source delivering this information. However, there is a gap in our knowledge of how people with schizophrenia use health information sources and their level of trust in these sources.

(2) As discussed in chapter two, knowledge of how people perceive a health threat can provide valuable insight into how they will behave if they become exposed to that health threat. There is evidence of a significant and consistent relationship between risk perception and health behaviours (Brewer et al. 2007). Specifically, a key finding from SARS research is a correlation between willingness to comply with protective measures, and the risk perception variables *perceived likelihood* and *perceived seriousness* of contracting the

infection (Leung et al. 2003; Cava et al. 2005). However, there is no research to the candidate's knowledge, exploring how people with schizophrenia perceive the threat of pandemic influenza. Knowledge of risk perception about pandemic influenza will be of value in preparedness and response planning.

(3) As indicated in chapter two, there is evidence that vaccination and infection control measures, including hand washing, social isolation and wearing a surgical face mask, can reduce the spread of respiratory viruses and, therefore, an individual's own risk of contracting an influenza infection (Jefferson et al. 2008). Epidemiological modeling has indicated that an effective response plan, including the implementation of protective behaviours, has the capacity to substantively reduce individuals' risk of being clinically affected by pandemic influenza, as well as the number of deaths. Therefore, knowledge of individuals' willingness to engage in protective behaviours is important. To the candidate's knowledge, following a search of the literature, there have been no studies examining the reported willingness of people with schizophrenia to adopt precautionary measures during a pandemic influenza.

(4) As discussed in chapter two, there is evidence that an individual's willingness to carry out a given protective measure in response to an influenza outbreak is influenced by their *perception of the effectiveness* of that protective measure, as well as their *perception of the risks* or difficulties associated with the protective measure. Therefore, there is value in acquiring knowledge on what people perceive as the benefits of, and barriers to, carrying out a

protective action. To the candidate's knowledge, following a critical examination of the scientific literature, there is no existing research examining how people with schizophrenia view vaccination, increased hand washing, wearing a face mask, or self isolation during a pandemic in terms of perceived benefits and barriers.

3.4 Aims of research project

The aim of the thesis research project is to extend the current knowledge base and understanding of:

(1) How much health information people with schizophrenia obtain from various information sources, as well as their level of trust invested in these sources. Although the main context of this aim in the thesis is to explore how a person with schizophrenia becomes informed about a pandemic influenza and what actions to take, knowledge of how health information *in general* is obtained, has an important wider value and application. This is especially relevant given the other significant medical comorbidities people with schizophrenia are vulnerable to, such as heart disease, diabetes mellitus and chronic obstructive pulmonary disease.

(2) How people with schizophrenia perceive risks associated with pandemic influenza.

(3) The willingness of people with schizophrenia to adopt protective measures during a pandemic influenza, if advised to by government health authorities.

(4) What benefits and barriers people with schizophrenia perceive in terms of adopting recommended protective measures during a pandemic influenza.

3.5 Research questions

Two key research questions and five hypotheses were framed to progress the investigation of the research project aims outlined above.

Research question 1: Do people with schizophrenia perceive a higher risk from pandemic influenza compared with people without schizophrenia?

Sub-question 1: How much health information is obtained from various information sources, and what is the level of trust in these sources, for people with schizophrenia compared with people without schizophrenia?

In order to have awareness that a health threat such as a pandemic influenza exists, an individual must receive information about its occurrence, characteristics and progress. In addition, in order for the health threat to be taken seriously there needs to be a level of trust in the integrity and accuracy of the information source reporting the health threat. Therefore, an exploration of the use of, and level of trust in, common health information sources

including doctor, the Internet, family and friends, television, radio, newspaper and magazines, is relevant component of the research project.

Sub-question 2: *How do people with schizophrenia perceive both their likelihood of contracting influenza during a pandemic and how serious this would be for them, compared with people without schizophrenia?*

As discussed in chapter two, the principal dimensions of risk are *perceived likelihood* of the threat occurring to an individual and the *perceived seriousness* of the threat. It is important that questions exploring these risk perceptions are framed as *conditional* risk questions i.e. it is made clear that the risk perception being enquired about is in the context of no protective measures being employed. For instance, an individual may perceive both dimensions of risk associated with pandemic influenza very differently in the presence, compared with the absence, of a vaccination. As described in chapter two, there is value in examining factors that have been found to influence perceived risk. These include perceived personal *vulnerability* (or susceptibility) to a threat, perceived *control* over the threat, *factual knowledge* of the threat, *knowledge of the disease experience,* and perceived *consequences*, including death.

Research question 2: How willing are people with schizophrenia to adopt protective measures during a pandemic influenza compared with people without schizophrenia, what factors influence this willingness and what are the perceived barriers to taking these actions?

Sub-question 3: *How willing are people with schizophrenia to <u>receive a vaccination, isolate themselves, wear a surgical face mask and to increase their frequency of hand washing</u> during a pandemic influenza compared with people without schizophrenia?*

In order to assess willingness to adopt protective measures against pandemic influenza, it is important to clarify which particular protective measures are being assessed. As discussed in chapter two, important preventative measures that can reduce the transmission of respiratory viruses include vaccination, increased hand washing, social isolation and wearing a face mask (which, as discussed in chapter two, can be used to reduce the risk of oneself contracting influenza from others or from spreading it to others).

Sub-question 4: *How willing are people with schizophrenia to adopt protective measures during a pandemic influenza compared with people without schizophrenia, <u>if advised to by government health authorities</u>?*

As discussed earlier, pandemic influenzas differ in their severity and lethality. The case fatality rate of the H1N109 virus was significantly lower than that of most seasonal influenza viruses. Therefore, it was seen as important to assess individuals' willingness to adopt protective measures in the context of recommendations given by governmental health authorities, especially in view of delayed availability of, and potential shortages of, specific vaccines during a pandemic influenza outbreak.

Sub-question 5: *How effective do people with schizophrenia perceive protective measures to be in a pandemic influenza and what are their perceived barriers to adopting these measures, compared with people who do not have schizophrenia?*

As described in Chapter two, health behaviours such as carrying out preventative measures against influenza, are influenced by what people view as the benefits of, and barriers to, these actions. Therefore, knowledge of perceived effectiveness and perceived barriers may assist in facilitating implementation of relevant protective measures during a pandemic influenza.

3.6 Research hypotheses

Five *a-priori* research hypotheses reflect the investigator's expectations regarding the outcome of the study.

Hypothesis 1:

People with schizophrenia attending mental health care services report obtaining less health information from common information sources compared with people attending a primary health care setting who do not have schizophrenia.

This hypothesis will explore socio-demographic factors as possible explanatory variables, in anticipated differences in use of information sources between people with schizophrenia and people in the general population.

Hypothesis 2:

People with schizophrenia attending mental health care services report having less trust in common health information sources compared with what people attending a primary health care setting who do not have schizophrenia.

This hypothesis will also explore socio-demographic characteristics as potential explanatory variables, for anticipated differences in levels of trust in health information sources between people with schizophrenia and the general population.

Hypothesis 3:

People with schizophrenia attending mental health care settings perceive a greater risk from pandemic influenza compared with people attending a primary health care setting who do not have schizophrenia, both in terms of their perceived likelihood of themselves contracting the influenza virus, as well as their perceived seriousness of contracting the virus.

Due to findings of less optimistic bias in people with schizophrenia compared with the general population (as discussed in chapter two), there is an expectation of greater perceived risk related to pandemic influenza for people with schizophrenia compared to people without schizophrenia. People with schizophrenia are seen as less likely to believe that the influenza virus would infect and cause harm to others but not themselves, or that they are somehow invulnerable to its potential negative impact. This hypothesis will explore socio-

demographic characteristics, affective factors, perceived likelihood of oneself contracting the virus, perceived seriousness of oneself contracting the virus, and perceived personal vulnerability to the pandemic as predictors of perceived **overall risk** from the pandemic influenza. Affective factors (which are viewed as particularly important in influencing threat appraisal) may be influenced by concurrent levels of psychological distress. Therefore, this hypothesis will also explore the role of psychological distress in pandemic influenza risk perception.

Hypothesis 4:

People with schizophrenia attending mental health care settings are less willing to undertake protective measures against a pandemic influenza than people attending a primary health care setting who do not have schizophrenia.

This hypothesis will explore potential links between socio-demographic variables and willingness to adopt protective measures, as well as exploring pandemic risk perception variables, perceived risks and benefits of potential protective actions, affective factors (including levels of psychological distress) and self-rated health as predictors of willingness.

Hypothesis 5:

People with schizophrenia attending mental health care settings have a different perception of barriers to carrying out protective measures against a

pandemic influenza compared with people attending a primary care health setting who do not have schizophrenia.

This hypothesis recognizes socio-demographic characteristics, especially employment status, socio-economic status and the presence or absence of children in the household, as factors likely to impact on what barriers or difficulties are perceived in adopting protective measures during a pandemic.

3.7 Research projects

In order to address the research aims, and the two key research questions, and associated hypotheses, a ***cross-sectional survey*** (with quantitative and qualitative components) was carried out. In addition, a qualitative follow-up study, comprising eleven ***in-depth interviews,*** was conducted out to further engage the research aims (described in Chapter 6). The cross-sectional survey was carried out over a four-month period (July - October 2009) during the swine influenza pandemic. The in-depth interviews were conducted in August 2014.

3.8 Conclusion

People with schizophrenia are vulnerable to influenza, with especially heightened health risks during an influenza pandemic. However, there are many gaps in the current knowledge base in the scientific literature, including

how information on health threats is acquired, how the risk of pandemic influenza is perceived, willingness during an influenza pandemic to carry out recommended protective measures, and how benefits and barriers related to carrying out these measures are perceived. This thesis and its hypotheses are addressing these core themes relevant to people with schizophrenia of how they can protect themselves from influenza, especially in the context of a pandemic, through recognition of, and response to, their heightened risk, by taking effective precautionary actions.

CHAPTER FOUR

CROSS-SECTIONAL STUDY: METHODOLOGY

4.1 Introduction

This chapter describes the methodology employed in the thesis cross-sectional study, including sample, procedure, ethics, instruments, and statistical analysis strategy.

Prior to completing the methodological formulation of the thesis research project, the candidate had conducted a pilot study, which helped shape the development of the thesis project. The pilot study was a small cross-sectional survey (n = 22) aimed at exploring people's health beliefs and associated affective responses to various existing and potential threats to their physical health. The threats examined included 'bird flu' (avian influenza), coronary heart disease, diabetes mellitus and hypertension. There were two groups of participants in the survey. The first group, recruited from both community mental health centres and general practices in the Australian Capital Territory, comprised those people who reported a mental illness (bipolar disorder, depression, and obsessive-compulsive disorder; four participants did not disclose which specific mental illness they suffered from). The second group, who were recruited only from general practice settings, comprised participants who reported that they did not suffer from a mental illness. Aspects of the medical disorders explored in the survey were: illness identity (symptoms of

the disorder); perceived consequences of the disorder; perceived control over the disorder (both personal control and treatment control); perceived degree of understanding of the illness; and emotional response to illness. Findings suggested consideration of a hypothesis that the people with a mental illness perceive coronary artery disease, diabetes mellitus and hypertension similarly to those participants who did not report having a mental illness. However, it also suggested consideration of hypothesis that people with a mental illness have different risk perceptions of 'bird flu' (e.g. that it is more common) compared with those in the general population.

The pilot study led the candidate to consider, as *feasible*, a larger research project examining risk perception and protective behaviours with respect to a serious influenza outbreak, in people with a mental illness. It provided the candidate with a familiarity of the general process and logistics of conducting such a research project, including issues of recruitment and research methods, as well as insights into particular challenges involved in implementing it in *local* health care settings.

4.2 Sample

In the thesis cross-sectional survey, a purposive sample of 309 participants was obtained from health care settings in the Australian Capital Territory (ACT), in Australia. Volunteers between the ages of 18 and 65 (inclusive) were recruited from thirteen general practices, and from mental health care settings,

comprising a hospital psychiatric inpatient unit, four community mental health centres, and a residential psychiatric rehabilitation unit. Inclusion and exclusion criteria are shown in Table 4.1.

Table 4.1 Cross-sectional survey: inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Mental health care group	• Age 18-65 (inclusive) • Attending one of the specified mental health care settings in ACT • Confirmed diagnosis of schizophrenia • Questionnaire completed satisfactorily • Signed consent form	• Unable to provide informed consent
General practice group	• Age 18-65 (inclusive) • Attending identified general practice in ACT • Questionnaire completed satisfactorily • Signed consent form	• A reported diagnosis of schizophrenia • Unable to provide informed consent

The research study involved two groups of participants: (1) people attending any of the mental health settings who had been diagnosed with schizophrenia (SCZ) by their treating psychiatrist, and (2) people attending a general practice (GP) setting. No participants in the GP group reported suffering from schizophrenia. A diagnosis of schizophrenia reported by a participant was confirmed by the candidate or Dr Reay contacting the treating psychiatrist of that patient. From a total of 386 questionnaires returned, there were 242 participants in the GP group, and 72 in the SCZ group, comprising 50 from

community mental health centres; 12 from the psychiatric inpatient unit; and 10 from the rehabilitation unit. One potential participant from the rehabilitation unit was excluded from the study due to a clear inability to provide informed consent. Four potential participants from the GP group, who had returned questionnaires, were outside (> 65) the required age range and were also excluded from the study. This resulted in 71 adults in the SCZ group, and 238 adults in the GP group, participating in the study (Figure 4).

Figure 4 Study design and participants
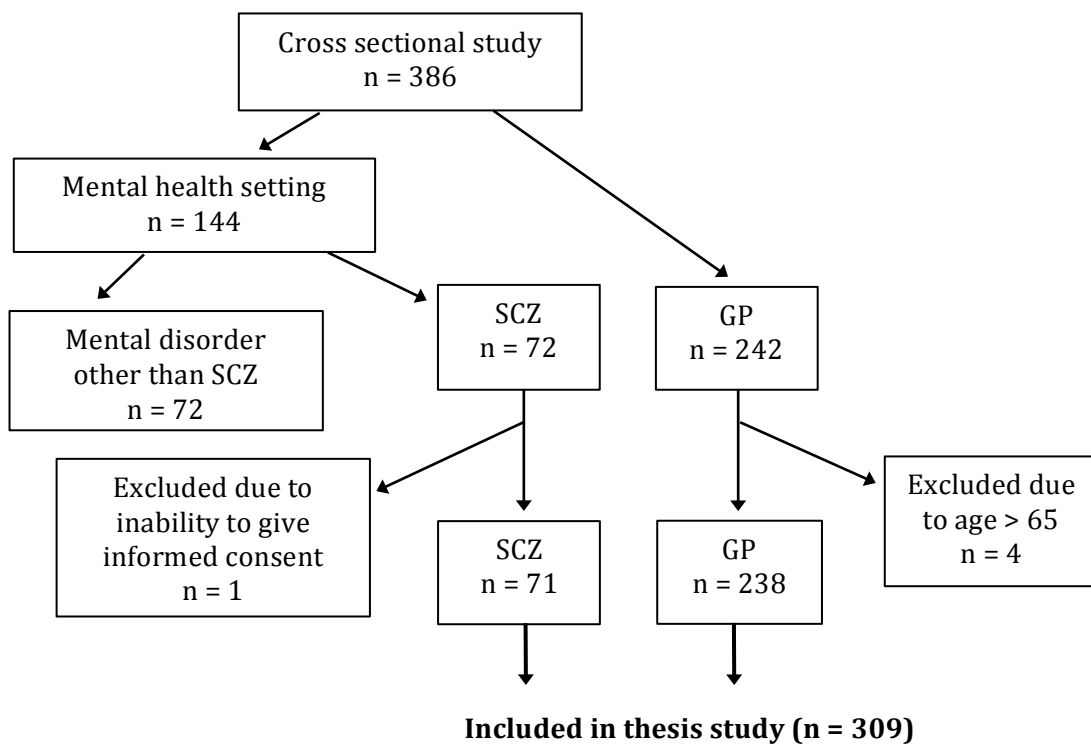
SCZ, schizophrenia; GP, general practice, CMHC, community mental health centre

A naturalistic sample of patients with schizophrenia was sought for which an adequate comparator could be found. People with schizophrenia not linked with health services were seen as being less likely to be accurately diagnosed

and more difficult to recruit. General practice attenders were viewed as a reasonable comparator group, accessible and likely to respond to the invitation to be involved in the study. Respondents in the SCZ group all had regular contact with a psychiatrist or trainee psychiatrist. In the hospital inpatient unit this was at least several times a week, and was not less frequently than third monthly in the community mental health centres and rehabilitation centre. The general practices were predominantly small urban group practices.

4.3 Procedure

Participants were recruited by providing posters and information brochures (Appendix 3) describing the study, in foyer areas and waiting rooms in the various health care settings, inviting patients to participate in the study. The candidate and his part time research assistant, Dr Reay, visited the hospital psychiatric ward on a regular basis (usually weekly) to ensure that posters and information brochures remained available, visible and accessible, and to encourage participation in the study. They did not directly approach individual patients but made brief announcements in the foyer areas where patients were sitting. They also enquired whether there were any issues potential participants would like clarified. Pens and questionnaire booklets were provided in these areas. Patients who were clearly not capable of providing informed consent, or did not have the capacity to complete the questionnaire, were excluded from the study.

Similarly, the candidate and Dr Reay visited the rehabilitation centre and invited residents there to participate in the study. A senior nursing staff member asked residents to gather in the foyer area if they were interested in possible participation in the study. A brief group meeting was held with these residents, inviting them to participate in the study and clarifying any issues or queries they raised.

The candidate had worked as a clinician in the recent past in all community mental health centers as well as in the hospital psychiatric ward and the rehabilitation unit. This facilitated communication with clinical and administrative staff in these settings, who were very cooperative and supportive of the research project. The candidate had discussed the research project with the team leaders in all recruitment settings prior to the survey, as well as with the Director of Clinical Services.

The candidate and Dr Reay separately visited general practices where the principal doctor or practice manager had agreed over the phone to involvement in the study. The candidate had worked as a general practitioner in the ACT for thirteen years and had a collegial affiliation with many of these practitioners, who gave their support and encouragement for the research project. Choice of general practices to be included in the study was based on an aim of achieving geographical and socio-economic diversity in the sample. The general practices were provided with a plastic folder containing information brochures, pens, survey questionnaires and consent forms. The questionnaires were

supplied in a quantity of ten at a time, so that any one practice did not contribute more than 20 completed surveys, in order to reduce any potential bias from sample clustering. The candidate and Dr Reay made phone calls periodically to the participating general practices to monitor progress and need for further questionnaires.

Patients included in the study were all judged as having the capacity to provide informed consent and to contribute in ways relevant to the aims of the study.

Participants were invited to complete a questionnaire (Appendix 4) that included socio-demographic characteristics as well items chosen to enable collection of the necessary data to test each of the hypotheses outlined in chapter three. The questionnaire also contained several items on health beliefs and broader physical and mental health issues, which the candidate is exploring, but which are not related to the thesis study. When completed, the questionnaires were returned by the participants to Dr Reay or the candidate in the hospital ward and rehabilitation unit, or to reception staff in the community health centres and general practices. Dr Reay or the candidate collected them within several days. A small financial award ($AU5.00) was offered to participants in recognition of their time and effort in completing the questionnaire.

4.4 Ethics

Ethics approval was obtained from the Australian National University, and ACT Health Human Research, Ethics Committees (Appendix 5). Written informed consent was obtained from all participants in accordance with the ethics committees' protocols. It was made clear on the consent form that involvement in the study was purely on a voluntary basis and would not interfere in ongoing clinical care in any way, or incur any costs. It was also emphasized in the consent process that volunteers would be de-identified and that they could cease their involvement in the study at any time. There were separate consent forms for general practice participants and participants in mental health settings (Appendix 6). These forms were identical except that the form for volunteers in a mental health setting requested consent for the candidate or Dr Reay to contact the treating psychiatrist to confirm a diagnosis of schizophrenia. The consent forms provided contact numbers of the candidate and research assistant in case a participant experienced distress or a problem they believed was connected with the research project and wished to discuss it. They also included contact details of a representative of the ACT Human Research Ethics Committee, if the participant chose not to speak with the researchers.

An approval was also obtained from the Survey Resource Group, a sub-committee of the ACT Human Research Ethics Committee which examines questionnaires for appropriate standards of structure and content for patients in the hospital psychiatric ward to participate in the study survey (Appendix 7).

The information brochure provided a summary of the aims of the research study, its potential benefits to the community and what participation in the study would involve. The brochure also contained the URL address of a website with helpful information on influenza, including how a person can reduce their risk of contracting it. Finally, the information brochure included contact details of a crisis counseling service in case involvement in the study caused a participant to feel distressed or at risk in any way (however, there was no feedback from any source during or after the study indicating that this had occurred).

A small financial award ($AU5.00) was offered in recognition of the time and effort of the participant in completing the questionnaire. Although there remains some debate over the ethics of paying volunteers for their involvement in research projects, there is evidence that 24-80% of biomedical research organizations pay at least some participants, including both well and ill volunteers (Dickert et al. 2002). This includes payment as an incentive (58%) as well as for other aspects of their participation, including time (87%), inconvenience (84%), travel (68%) and incurring risk (32%). There is evidence that small cash payments increase survey response rates (Doody et al. 2003; Ulrich et al. 2005). Ulrich et al. conducted a randomized controlled trial in the US (n = 3,900) and found that a modest cash payment of $US5 was associated with a response rate of 64.2%, compared with a response rate of 44.7% for the opportunity to enter a lottery, and 42.2% for the control group (no incentive). Therefore, it could also be argued that payment of participants is

not only a mark of respect for their time and effort but also respects their involvement by improving the likelihood of recruitment and retention of volunteers, and therefore of obtaining an adequate sample size. This would provide greater statistical power and increase the chances that the volunteer participated in meaningful and productive research. Finally, the International Guidelines for Biomedical Research Involving Humans (Council for International Organizations of Medical Sciences 2002) endorses payment for participation in research as long as the payment is not large enough to cause undue inducement.

A funding application was made to the Private Practice Fund at The Canberra Hospital. The Minor Grants Subcommittee considered this on 14 July 2009 and a decision was made to fund the research project for $AU2,500 (Appendix 8).

4.5 Instruments

The candidate developed a survey instrument for the cross-sectional study that was capable of addressing the aims of the research project and to test the hypotheses discussed in chapter three. The survey instrument was required to:

(1) Evaluate how much health information people with schizophrenia attending health care settings acquire from various information sources, and the level of trust in these sources, compared with people without schizophrenia, attending a primary care setting.

Specific information sources (i.e. television, radio, newspaper, the Internet, magazines, doctor, and family and friends) were chosen for inclusion in the survey instrument to: (1) be in keeping with other studies in the literature evaluating serious outbreaks of respiratory infection discussed in chapter two (e.g. Brug et al. 2004), and (2) because they were seen as representative of the broader Australian community. Five-point Likert scales were chosen so that data could be generated from Likert responses to test Hypotheses 1 and 2 for each protective measure, using regression analysis. The questionnaire item ("How much information about health matters do you yourself get from the following……television, radio, newspaper, the Internet, magazines, your doctor and family and friends") enquired about health matters in *general* rather than about pandemic influenza *specifically,* for two reasons. First, no other study to the candidate's knowledge has explored which health information sources are utilized by people with schizophrenia, and given the extensive medical morbidity described in chapter one, it was seen as useful to explore access of health information more broadly. Second, people who contract a pandemic influenza virus may experience an exacerbation of other existing medical conditions such as COPD or diabetes mellitus, and therefore, need to seek information about these disorders as well as influenza, in order to know what actions to take in these circumstances.

(2) *Evaluate the risk perceptions about the H1N109 influenza pandemic of people with schizophrenia in health care settings, compared with people without schizophrenia, attending a primary care setting.*

As discussed in chapter two, knowledge of individuals' risk perception of health threats is useful as it has been shown to have the capacity to influence health behaviours, such as adopting protective measures. This has been demonstrated for seasonal influenza as well as for SARS. It was seen as important to explore the *core dimensions* of risk i.e. *perceived likelihood* of contracting swine flu and *perceived seriousness* of contracting swine flu, as well as participants' *overall perceived risk* to themselves from swine flu. In addition, the survey tool was developed to include items evaluating *"risk as feelings"* ("How vulnerable does it make you *feel* knowing that there is a global influenza pandemic?", as well as items on one's predicted affective response in the event of contracting swine flu in the future). Likert scales were chosen to generate data to enable comparisons between people with schizophrenia and people in primary health care settings without schizophrenia i.e. to test Hypothesis 3. Factors that have been found to influence the perception risk (discussed in the chapter two) were also included in the development of the survey instrument. These included *perceived control* over contracting swine flu, *factual knowledge* of swine flu, *knowledge of the illness experience* of influenza and *current physical health* status. It was considered that data generated from these items in the questionnaire could be usefully explored as potential predictor variables for perceived risk. Current psychological distress was also seen as an important variable that may influence perceived risk. Therefore, a Kessler-10 Psychological Distress Scale was included in the survey tool.

(3) *Evaluate the willingness of people with schizophrenia in health care settings to adopt protective measures against a pandemic influenza, compared with people without schizophrenia attending a primary care setting.*

In order to permit a comparison with base-line data collected by Barr et al. (2008) in a study of generic pandemic influenza risk perception and willingness to comply with protective measures in the general population of New South Wales (discussed in chapter two), face mask, isolating oneself from others and having a vaccination were included as protective measures. Although not included in the Barr et al. study, hand washing was also chosen in the development of the survey tool, as it is a simple and effective infection control measure. Again, 5-point Likert scales were chosen for the survey tool to enable a comparison between people with schizophrenia attending a mental health care setting and people attending a primary care setting without schizophrenia, using data from Likert responses.

(4) *Evaluate the perceived effectiveness of, and barriers to, adopting protective measures.*

In order to try to gain insights into people's willingness and confidence in being able to carry out protective measures, the survey tool was developed to ascertain how *effective* the measures were perceived to be and what the perceived *barriers* to carrying out each measure were. Likert scales were chosen to evaluate perceived effectiveness, for similar reasons as above. To obtain a more personalized, less restricted, and more spontaneous understanding of how people perceived barriers to carrying out protective

measures, open-ended questions were considered useful and appropriate, and were included in the tool.

The completed survey instrument (Appendix 4) comprised the following items:

(A) Socio-demographic characteristics

Data were collected on socio-demographic characteristics that were viewed as relevant to the principal themes of the study. These variables included age (calculated from date of birth), gender, presence of children in the home, non-English languages spoken in the household, whether or not the participant was living alone, employment status, highest level of educational attainment, and estimated yearly household income. Collection of these data also enabled for adjustment in regression analyses.

Analysis and implications

Data analyses were carried out using SPSS 17.0 for Windows. A core issue in choosing the most effective and appropriate analysis strategy is whether to use *parametric* or *non-parametric* statistical methods. There has been a long-running (and often heated) debate on whether data from Likert and Likert-like scales should be treated as *ordinal* in nature (to be analyzed with only non-parametric tools), or whether the data can be more effectively analysed through *means*, as *continuous* data, using parametric statistical tools (Knapp 1990; Clason & Dormody 1996; Kuzon Jr et al. 1996; Jakobsson 2004; Jamieson 2004; Carifo & Perla 2007; Norman 2010).

Objections raised about using a parametric approach in the analysis of Likert scale data include: (1) response categories have rank order (and therefore, it is argued that medians rather than means are appropriate) but intervals between responses cannot assumed to be equal e.g. the intensity of belief/feeling between *strongly disagree* and *disagree* may not be equivalent to the intensity of belief/ feeling between *agree* and *strongly agree* or other two adjacent response options (Cohen et al. 2000), (2) data from responses in Likert scales are often skewed i.e. not normally distributed, and this violates an assumption often seen as necessary for the use of parametric tools, (3) parametric techniques assume homogeneity of variance in the population samples being compared (i.e. the variability of scores for each group is similar) and this may not be present in Likert scale responses.

Proponents of the view that parametric tools are not appropriate for Likert scale analysis argue that the numbers used in the Likert scale (e.g. 1,2,3,4,5) are merely descriptive markers, or labels, of the given response (and could be replaced by A, B, C, D, E) and numerically meaningless. For example, it may not be feasible to infer that the fourth option response is four times the magnitude of the first response option. Kurzon Jr et al. (1969) posit that the average of "fair" and "good" is not "fair-and-a-half". Another assertion made by researchers adopting this school of thought is that true interval/continuous data should have an actual "unit of measure" (e.g. years for age, grams for weight etc.). If a participant in a study obtains a mean score of 3, one should

be able to state three "what", which it has been argued may present a difficulty in a Likert scale.

Despite these concerns, there have been strong arguments made for the use of parametric techniques in analyzing data from Likert and Likert-like scales, and that violations of parametric assumptions have minimal or no effect on conclusions in most cases (Norman 2010). It has been argued that it is important to use statistical procedures that maintain the richness of the data (Knapp 1990). Continuous data provide more information and more statistical power than ordinal data. Although conceptually Likert scale data are indeed ordinal in nature, there are empirical studies dating back to Pearson in 1931 that have found robustness for parametric tests (including t-tests, ANOVA, Pearson correlations) on data with skewed and non-normal distributions and with small sample sizes (Pearson 1931; Boneau 1960; Glass et al. 1972; Carifo & Perla 2007; Norman 2010). Norman (2010) concludes his analysis of the employment of parametric techniques for Likert data analysis (including t-tests, ANOVA, Pearson correlation, linear regression) with this summary:

> "Parametric statistics can be used with Likert data, with small sample sizes, with unequal variances, and with non-normal distributions, with no fear of 'coming to the wrong conclusion'. These findings are consistent with empirical literature dating back nearly 80 years. The controversy can cease (but probably won't)" (p.631).

With respect to 'units' for a Likert scale mentioned above, one should bear in mind that Likert scales are often used in psychological research to measure people's attitudes and beliefs, which may lack more concrete units. Scales and instruments used in social and psychological studies which have a large range of numerical scores such as the Hamilton Depression Scale, still face this issue. Even Rensis Likert in his original paper identified that there might be an underlying continuous variable characterizing the participants' opinions or attitudes and this underlying variable is interval in nature (Likert 1932).

Another important element in this debate is that Likert formats are not all the same. In addition to varying in number of options, they vary in structure. The typical format consists of options ranging from strongly disagree through to neutral (neither agree nor disagree) and on to strongly agree. This format is essentially binary (Agree versus Disagree). However, some Likert-like items, such as the one chosen for this survey, range from "not at all" (i.e. an arbitrary zero point) to "extremely" through clear, easily understood numbered increments, the wording of which suggest equal intervals in a magnitude continuum i.e. from "not at all" to "a little" to "moderately" to "very" to "extremely". It could be argued that in this context, such a scale, especially if numbered from low to high (e.g. 1-5 or 0-4) has a continuous 'interval' quality.

In light of the controversy described above, the candidate will provide both *parametric* and the *non-parametric* equivalent for the main Likert data analyses, as well as the test for homogeneity of variance.

As seen in Table 4.2 an independent-samples t-test showed no statistically significant difference between the mean age in the SCZ group (36.6 years; SD 14; range 43 [19-62]) and the GP group (36.1 years; SD 9.7; range 47 [18-65]), with Levene's test showing non-homogeneity of variance ($p < 0.01$). However, there were significant differences in other socio-demographic variables. Seventy per cent of participants in the SCZ group were male compared with 34% in the GP group. Chi-square test confirmed this as a statistically significant difference. As might be anticipated there was also a disparity between the two groups in estimated household annual income and highest level of education attained. Approximately 70% of people with schizophrenia estimated their annual household income to be below $20,000 compared with approximately 20% in the GP group. Conversely, only 3% of people with schizophrenia estimated their annual household income to be above $80,000 compared with 43% in the GP group. Almost 50% in the GP group reporting attainment of a university degree compared with less than 10% in the SCZ group. Chi-square test confirmed statistically significant differences between the SCZ group and the GP group for highest level of education attained, estimated household annual income, employment status, living alone, and children in the household. There was no statistically significant difference between the two groups for non-English languages spoken in the home.

Potential methods to control for these differences and reduce confounding were considered including logistic regression, matching, and stratification. A

Table 4.2 Socio-demographic characteristics (n = 309)

	SCZ (n=71)	GP (n=238)	Statistic[#]
Age			t = 0.36, p = 0.72
			(F = 22.91, p < 0.01*)
Mean	36.1	36.6	
SD	9.7	14.0	
Range	43 (19-62)	47 (18-65)	
Gender			χ^2 = 28.9, p < 0.01*
Male	70%	34%	
Highest level of education			χ^2 = 50.7, p < 0.01*
None	11.3%	1.7%	
Year 10 certificate	31.0%	15.1%	
Year 12 certificate	25.4%	20.2%	
TAFE certificate/diploma	23.9%	14.3%	
University degree	8.5%	48.7%	
Estimated yearly household (gross) income ($)			χ^2 = 73.3, p < 0.01*
< 20,000	70.1%	19.6%	
20,000-40,000	13.4%	4.0%	
40,000-60,000	10.4%	9.4%	
60,000-80,000	3.0%	14.0%	
> 80,000	3.0%	43.0%	
Currently employed	21.1%	91.7%	χ^2 = 50.3, p < 0.01*
Lives alone	33.8%	12.2%	χ^2 = 16.5, p < 0.01*
Children in household	5.6%	43.7%	χ^2 = 33.2, p < 0.01*
Language other than English spoken in household	20.0%	22.5%	χ^2 = 0.07, p = 0.79

* statistical significance (p < 0.05); SD, standard deviation; GP, general practice; SCZ, schizophrenia

[#] Statistic includes: independent-samples t-test with Levene's test for homogeneity of variance; Chi-square test

decision was made to use logistic regression analysis, which was viewed as a very useful statistical tool for this study. As opposed to stratification, where one potential confounder would be eliminated, or matching to deal with a limited number of potential confounders, logistic regression was able to control for multiple confounders (within limits imposed by power considerations) in the thesis study. In addition, it would enable *exploration* of the socio-demographic variables associated with the outcomes of interest. An identified disadvantage of matching (e.g. on socio-economic status) for this study was that variables of interest such level of education, household income, and employment status, cannot then be assessed as potential 'risk factors', as they are they same in the cases and controls (i.e. in the matched pairs). Furthermore, the candidate wished to compare people with schizophrenia with the broader community, not just a small atypical 'tip' of the general population (exploratory analysis revealed only a small n [= 35x2] when the comparator group was matched on age, gender, employment status and household income, even when the tolerance for age was set at 5).

Given that 80% of participants with schizophrenia were unemployed and 70% were in households earning less than $20,000 per annum, correlational analysis was performed (using Pearson's product-moment correlation coefficient) to explore the bivariate relationship between employment status and income, which unsurprisingly was found to be substantive ($r = 0.7$, $p < 0.001$). In addition, there were significant negative correlations between a diagnosis of schizophrenia and income ($r = 0.5$, $p < .01$). Given that

the logistic regression model functions best when predictor variables are strongly related to the dependent variable but not strongly related to each other (Pallant 2007), employment status and highest level of education were used in the model to represent socio-economic status for between-group analyses.

Statistical power issues

Power is an important consideration in the analysis strategies, in order to avoid a type II error i.e. to correctly reject a false null hypothesis. Although $\geq$ 80% (i.e. $\geq$ 0.8) is often viewed as the desirable level of power, a magnitude of $\geq$ 60% is typical of many published psychological studies. The candidate was mindful that power is determined by the effect size, the sample size, the critical value, and the statistical procedure being used. Given the paucity of existing research in the domain of the thesis hypotheses, the challenge with power calculations estimating required sample size is uncertainty about effect size. With respect to the actual sample size obtained, and the critical point (alpha level of significance set at 0.05), it is useful to examine what effect sizes could be detected with power = 0.60. Using G*Power 3.1, independent samples t-test was found to have the capacity to detect an effect size of Cohen's d = 0.3 (i.e. a relatively small effect). With respect to logistic regression analysis, the most vulnerable statistical procedure was *within-group analysis* of the SCZ group (due to the relatively small n = 71) especially when the predictor variable was dichotomous, such as *gender*, *employment status*, *living alone*, *children in the household* and *languages other than English spoken in the household*. For instance, with the assumption of

'event rate' = 0.5, a SCZ within-group logistic regression analysis of gender as a predictor variable could only detect an Exp(B) (i.e. odds ratio) of 3.38 or larger. For the GP group with its larger sample size of 238, an Exp(B) of 1.85 or larger could be detected. For between-group logistic regression analysis (n = 309) an Exp(B) of 1.83 or larger could be detected.

An alpha of 0.05 was used for the level of statistical significance for all analyses. A Bonferroni correction was considered, to reduce the chance of an inflated Type I error, but thought to be overconservative.

(B) Use of and trust in information sources

The questionnaire included items on how much information on health matters participants obtained from various sources including doctor, the Internet, television, radio, newspapers, magazines, and family and friends. Participants responded on a 5-point Likert-like scale. Possible responses included: 1 = none, 2 = a little, 3 = a moderate amount, 4 = a lot and 5 = an extreme amount. They were then asked to rate their level of trust in each of these sources as providers of health information, using the same scale. Specifically, participants were asked:

(1) How much information about health matters do you yourself
get from the following?..... [television, radio, newspaper, Internet, magazines, your doctor, family or friends]

(2) How much trust do you have in the following as sources of information on health?.......[television, radio, newspaper, Internet, magazines, your doctor, family or friends]

Analysis strategy

Data collected from responses to the Likert items were used to compare the amount of health information gained from a given source, by people with schizophrenia with that reported by people attending a general practice setting, thereby enabling Hypothesis 1 to be tested. Similarly, the level of trust in given information sources, in the two groups, was compared using the data from the Likert responses described above, allowing testing of Hypothesis 2.

Data were examined for significant differences between the SCZ (n = 71) and GP (n = 238) groups in the reported amount of information gained from each source and the level of trust invested in it, using independent-samples t-test, as well as the non-parametric equivalent, the Mann-Whitney U test. Correlation between amount of information obtained from a given source and the level of trust in that source, was calculated using a Spearman rho. Binary logistic regression was used to explore the relationship between the 'information' and 'trust' Likert data as dependent variables (separately) and various independent variables (including socio-demographic characteristics), and to enable adjustment for potential confounders.

For the binary logistic regression analyses, Likert responses were dichotomised into either (1) *none,* or *a little*, or (2) *a moderate, a lot* or *an extreme amount*, of information gained or trust invested. This enabled a comparison to be made between the SCZ and GP groups in terms of "at least a moderate amount of information" obtained from a given information source

and, "at least a moderate amount of trust" invested in that source. This comparison, using odds ratios generated by logistic regression then enabled testing of Hypotheses 1 and 2. Ordinal regression was not used because the proportional odds assumption ('test of parallel lines') was violated.

The procedure, using SPSS, for this binary logistic regression analysis was as follows. The re-coded dichotomized Likert response (*none or a little* = 0, versus *at least a moderate amount* = 1) for a given information source, was chosen as the categorical dependent variable and moved into the **Dependent** box. After entering the schizophrenia absent or present variable (0,1) into the **Covariates** box using the **ENTER** method, crude odds ratios were obtained and recorded. Next, the variables identified above as potential confounders were also entered into the **Covariates** box using the ENTER method. Where appropriate predictor variables were moved into the **Categorical Covariates** box, and adjusted odds ratios were subsequently calculated by the software. The adjusted odds ratios appeared as Exponential (B) values (with 95% confidence intervals) in the **Variables in the Equation Table** SPSS output.

Within-group multiple logistic regression analyses were performed. Socio-demographic characteristics were used as the independent (predictor) variables, and amount of information obtained, and level of trust, were the dependent variables. As with between-group analysis, the **ENTER** method was used.

(C) Pandemic influenza risk perception

The questionnaire included items examining participants' perception of their overall personal risk from swine flu ("Overall, what do you see as your risk from human swine influenza if you took no protective measures?"), as well as specific risk perception dimensions including:

(i) Perceived likelihood of themselves contracting swine flu

What do you see as your own risk of catching human swine flu in Australia during the current global pandemic if you took no special precautions (such as wearing a face mask, having a vaccination, increasing hand washing or isolating yourself)?

(ii) Perceived seriousness if infected with swine flu

If you caught human swine flu in Australia during the current global pandemic how serious do you think it would be for you?

(iii) *Feeling* vulnerable as a result of the current swine flu

How vulnerable does it make you feel knowing that there is a global influenza pandemic?

In addition, there were items in the questionnaire examining factors which, as indicated in chapter two, can influence risk perception, including:

(i) Perceived control (i.e. ability to avoid contracting swine flu)

To what extent do you believe you could avoid catching human swine flu in Australia during the current global pandemic?

(ii) Anticipated own affective response if swine flu were contracted (separate items for "afraid" and "depressed")

If you caught the swine flu during the current outbreak in Australia, how do you think it would affect you emotionally?

(iii) Factual knowledge of the disease (symptoms and duration of swine flu)

(iv) Knowledge of the disease experience

Have you or someone close to you ever suffered from a serious influenza in the past?

Participants responded on a 5-point Likert-like scale (except for "knowledge" items). Responses included: 1 = Not at all, 2 = A little, 3 = Moderately, 4 = Very, 5 = Extremely. A "Don't know" response was also included for appropriate questions. Items relating to perceived personal risk from swine flu, and likelihood of contracting swine flu, were *conditional* on no precautionary actions being taken. As discussed in chapter two, a response to an *unconditional* risk enquiry can be ambiguous and difficult to interpret. For instance, if a respondent answered "a little" to an unconditional enquiry about perceived likelihood of contracting influenza, this could be because they believe the virus is not very infectious and therefore the risk is low. On the contrary, it could indicate they believe the risk is high without a vaccination and so they intend to have one, which then renders their perceived risk low.

Factual knowledge was assessed by asking participants to:

(1) Name three symptoms that might occur in someone with pandemic influenza. Acceptable answers included: fever, headache, aches and pains, chills, rigors, fatigue, sore throat, cough, rhinorrhoea/runny nose, sneezing, blocked nose, watery, sore or red eyes, nausea, vomiting or loss of appetite (Akiskal et al.1999; Centres for Disease Control and Prevention 2010).

(2) Indicate how long a human swine influenza illness would last on average in an otherwise healthy individual by choosing one of three options: 1 = One week (*correct*), 2 = Three weeks, 3 = Three months (Government of Western Australia, Health Department 2009).

Scoring for factual knowledge was dichotomous: 0 = either or both questions answered wrongly or inadequately; 1 = both questions answered correctly.

Knowledge of the disease experience was measured by asking participants whether they, or someone close to them, had suffered from a significant influenza illness in the past. Response options included either *Yes* or *No*. Since the risk associated with influenza is heightened in the presence of concurrent medical illness, the questionnaire included the Single Item General Self-Rated Health Question. This is an easily administered, validated measure (DeSalvo et al. 2005) that has been used in other H1N109 influenza risk perception studies (Cowling et al. 2009). In addition, the 10-item Kessler Psychological Distress Scale (K10) was included to enable adjustment for

psychological distress (Kessler et al. 2002), which may also influence risk perception. The K10 is a 10-item validated self-report scale intended to yield a global measure of distress based on questions about anxiety and depressive symptoms that a person has experienced in the most recent 4-week period. In addition to K10 'total score', subscales of the K10 were used, including an *anxiety subscale*, a *depression subscale*, and a dichotomous measure, *K10 (total score) ≥ 20* versus *K10 (total score) < 20*. The anxiety subscale provides a composite score from responses to the four questions in the K10 relating to anxiety. Similarly, the depression subscale provides a composite score from responses to the six remaining depression-related questions. These sub-scales have been validated and used in research by other authors (Reavley et al. 2011). The dichotomous measure was chosen in the context of research suggesting that scores of below 20 are not associated with significant levels of distress and are not consistent with a depressive or anxiety disorder. In contrast, scores of 20 or above are associated with significant distress levels and are consistent with a diagnosis of a depressive or anxiety disorder: 20-24, mild depressive or anxiety disorder; 25-29, moderate depressive or anxiety disorder; 30-50, severe depressive or anxiety disorder. This cut-off score of 19 has been shown to have a sensitivity of 70% and specificity of 90% (Andrews & Slade 2001; Australian government, National Mental Health Strategy 2005).

Analysis strategy

The data were examined for significant differences in H1N109 pandemic influenza *risk perception* between the SCZ and GP groups, using independent-sample t-test, Chi-square test, and logistic regression analysis. As for the information sources analysis described earlier, odds ratios were obtained after Likert responses were dichotomised into either (1) *none,* or *a little,* or (2) *moderately, very* or *extremely*, enabling testing of Hypothesis 3. In addition to crude odds ratio scores, adjusted odds ratios were calculated controlling for age, gender, socio-economic status, children in the household, living alone, non-English language spoken in the household, knowledge of influenza experience, K10 scores and the Single Item General Self-Rated-Health Question. These variables were chosen as they were considered likely to impact on influenza risk perception. In addition, *week of participation* was also adjusted for, given that this study extended over a four-month period. Despite *initial* widespread concern and intense media attention it became more apparent over time that the H1N109 virus was not associated with a high fatality rate. Awareness of this was seen as potentially influencing core aspects of risk perception, and therefore needed to be (and was) controlled for.

Within-group analyses were performed using multiple logistic regression in order to explore the relationship between: (i) demographic variables, and risk perception dimensions and factors, as *independent* variables, an (ii) perception of personal overall risk as the *dependent* variable. Risk perception (*overall* perceived risk as well as the core dimensions - perceived *likelihood*, perceived

severity, and perceived *vulnerability*) was examined with respect to gender, education and income using an *ecological* approach (with frequencies and chi-square tests, exploring the data at a group level) as well as an *analytical* approach (with logistic regression, exploring the data at an individual level).

(D) Willingness to adopt recommended protective measures during a pandemic influenza

The questionnaire included items examining participants' willingness to adopt precautionary measures during the pandemic influenza in Australia if advised to by government health authorities. The protective actions included receiving a vaccination, isolating oneself from others if necessary, wearing a face mask, and washing one's hands more frequently. Participants responded on a 5-point Likert scale. Possible responses included: 1 = Not at all willing, 2 = A little willing, 3 = Moderately willing, 4 = Very willing, 5 = Extremely willing. A "Don't know" response was included for vaccination. Specifically, participants were asked:

In the case of an emergency situation such as an influenza pandemic, government authorities might request cooperation from the public in a number of ways. How willing would you be to …..[each protective action – vaccination, increased hand washing, isolating oneself from others, wearing a face mask - enquired about individually]…..?

As discussed in chapter two, these questions were used in a relatively recent study of the general population of New South Wales, and on field-testing were

found to be reliable, with kappa ranging from 0.25 to 0.51 (Barr et al. 2008). There are different kinds of masks that are available for use in the event of a pandemic, including surgical masks, P2 masks (P2 respirators) and Powered Air Purifying Respirators (PAPRs). However, the general public does generally not require use of P2 respirators and PAFRs. A decision was made to use the term 'face mask' rather than 'surgical mask', as it was viewed the latter might confuse people (especially people with low educational attainment), leading them to think this question implied some connection with an operating theatre. In addition, the candidate observed that all adults participating in informal field-testing, interpreted the term 'face mask' to denote a surgical mask. Finally, for comparison reasons the candidate chose to use the same term as used in the study of the NSW general population above (i.e. 'face mask').

Likert responses were also sought for perceived effectiveness, risk of adverse reaction (for vaccination) and self-efficacy. Self-efficacy was measured by specific question items, one for each protective action except hand washing, as listed below:

(i) How confident are you that once you decided to have a flu vaccination, you would be able to actually go ahead and get it done?

(ii) How confident are you that once you decided to isolate yourself from others, you would be able to actually go ahead and do this?

(iii) How confident are you that once you decided to wear a face mask, you would be able to actually do ahead and do this?

In the case of vaccination, additional information was sought for concern about 'catching the flu' from a vaccination. Specifically, participants were asked:

How concerned are you that you may actually get the flu from having a flu vaccination?

Since the risks associated with influenza are heightened in those with concurrent medical illness, and this may impact on willingness to undertake a protective action, the Single Item General Self-Rated Health Question was relevant, as for risk perception. Similarly, the 10-item Kessler Psychological Distress Scale was seen as important to enable adjustment for current psychological stress and anxiety, which have been shown to impact on willingness to adopt protective measures, as discussed in chapter two.

The rationale for the inclusion of 'willingness' items in the questionnaire was to gather data to enable testing of Hypothesis 4, that people with schizophrenia are less willing to adopt protective measures than people without schizophrenia attending a general practice. In addition, the data obtained permitted the candidate to examine for predictors of willingness such as risk perception variables and self-efficacy. Finally, the data collected from the survey tool make it possible to adjust for confounders, for willingness, such as current health and current levels of psychological distress and anxiety.

Analysis strategy

The data were examined for differences between the SCZ and GP groups regarding willingness to adopt protective measures during the influenza pandemic, using independent-samples t-test, Mann-Whitney U Test and logistic regression analysis. Again, for binary logistic regression odds ratios

were obtained after Likert responses were dichotomized into: (1) *not at all,* or *a little*, versus (2) *moderately, very* or *extremely*, enabling testing of Hypothesis 4. Ordinal regression was not used because the proportional odds assumption (test of parallel lines) was violated.

In addition to crude odds ratio scores, adjusted odds ratios were calculated in the between-group analyses, controlling for factors considered likely to impact on willingness to undertake precautionary measures, as potential confounders. These included adjustments for age, gender, socio-economic status, living alone, children in the household, non-English language spoken at home, week of participation, general self-rated health, previous influenza experience and K10 scores (total score, as well as anxiety and depression subscale scores, and K10 $\geq$ 20 versus K10 $<$ 20).

Within-group analyses using multiple logistic regression were performed to examine for significant predictors of willingness to take protective actions. Given the relatively small numbers of participants in the SCZ group, the socio-demographic variables included as independent variables were restricted to age, gender, employment status and highest level of education. Principal predictors of willingness to adopt a given protective measure included in the analysis were: (1) risk perception variables relating to the H1N109 global influenza pandemic, and (2) perceived effectiveness and self-efficacy for each of the precautionary measures (and risk of adverse reaction in the case of vaccination). Anticipated fear or depressed mood in the event of contracting

swine flu, were also analysed as predictors of willingness to undertake protective measures.

(E) Perceived barriers to adopting protective measures against a pandemic influenza

The questionnaire included open-ended questions enquiring about what participants viewed as potential barriers to carrying out each of the four protective measures (vaccination, social isolation, wearing a face mask and increased hand washing). Specifically, participants were asked:

What might be difficult for you about ……[each protective action asked about individually]…..? Please name three things.

The rationale for this qualitative aspect to the research study was to enable testing of hypothesis 5, that people with schizophrenia perceive barriers differently to people without schizophrenia attending a general practice. In addition, it was seen as helpful to have knowledge of these perceived barriers in order to find ways of enhancing preventative behaviours in a vulnerable group of people in a pandemic influenza.

Analysis strategy

Responses to open-ended questions exploring perceived barriers from all participants were analysed and themes were identified. Individual responses were then coded into one of these themes. Themes with fewer than 5 responses were excluded. A comparison between the SCZ group and GP groups was made by obtaining the frequency of each identified theme.

4.6 Strengths and limitations

The purposive sample used in this study is seen as having both strengths and limitations. In terms of advantages, it was an effective and feasible way of recruiting participants. It also ensured that participants in the SCZ group were likely to be correctly diagnosed, as they were clinically assessed and appraised by specialist psychiatrists at the time of the survey. Using all of the general population of the ACT as the sampling frame would have presented challenges in this regard, needing to rely on a diagnosis of schizophrenia by self-report or administering a lengthy diagnostic tool. It is likely also to have placed limitations on the number of people with schizophrenia recruited. Disadvantages of using a non-probability sample were the possibility of recruitment ('self-selection') bias, and limitations on the ability to generalize the results. Ability to consent to participation in the study by participants with schizophrenia was seen as a useful reflection of their level of functioning but also of potential source of bias in the sample, due to the exclusion of individuals with poor functional status. There were significant differences in socio-demographic profiles of the two groups, which is a 'real world' finding and forms part of the vulnerability of people with schizophrenia. The methodology addresses these differences by identifying them, and adjusting for them in the analyses. There is the potential for current psychotic symptoms, or mood symptoms, to influence the perception of people in the schizophrenia group. However, an attempt was made to adjust for psychological distress using the 10-item Kessler Psychological Distress Scale. Referential psychotic symptoms in schizophrenia have the potential to influence responses to the

questionnaire items on information sources. People experiencing hallucinations and/or delusions of reference may have the experience of 'receiving special messages' from the television, radio, Internet or print media, which may affect their perception of these media. The candidate acknowledges that there are inherent methodological issues in developing a purpose-designed survey tool. However, the thesis survey was based on a soundly field-tested (reliability and convergent validity) questionnaire assessing risk perception and willingness to adhere to protective measures, published the literature. In addition, the survey was approved by the Survey Resources Group (a sub-committee of the ACT Human Research Ethics Committee which examines surveys for appropriate standards and quality).

Due to the relatively low number of patients with schizophrenia compared with those attending a general practice setting, there are limitations in statistical power, especially for the SCZ within-group multiple regression analyses. Finally, a limitation of the study is the low level of clinical information about the participants. For the people in the SCZ group, this includes the severity and duration of their psychotic illness and for the GP group, the precise reason for their visit to the general practitioner. However, ascertainment of this information was seen as carrying the risk of rendering the questionnaire potentially overburdensome to participants.

4.7 Summary

The study is a cross-sectional survey. The survey tool was developed to address the research aims and hypotheses previously described. It was designed to compare the responses of 71 adults with schizophrenia attending mental health care settings in the ACT, with the responses of 238 adults without a diagnosis of schizophrenia, attending a general practice setting in the ACT, to questionnaire items on: amount information obtained from, and level of trust invested in, health information sources; risk perceptions related to the H1N109 pandemic influenza; willingness to adopt recommended protective measures against the pandemic if advised to by government authorities; and perceived barriers to carrying out these protective measures, as well as their perceived effectiveness. Variables thought likely to influence these factors were adjusted for as potential confounders. The survey used Likert scales as the principal measure (similar to many other influenza risk perception studies, as discussed in chapter two) but open-ended questions and binary Yes-No questions were also employed. The questionnaire included the 10-item Kessler Psychological Distress Scale to enable adjustment for psychological distress, and the Single Item General Self-Rated Health Question. Both parametric and non-parametric tools are employed in data analysis of the Likert scale responses.

CHAPTER FIVE

CROSS-SECTIONAL STUDY: RESULTS

5.1 Use of, and trust in, health information sources

5.1.1 Introduction

Access to, and utilization of, relevant information sources is essential in order to make informed decisions about health threats, including those imposed by a pandemic influenza. However, there is paucity of research exploring how people with schizophrenia obtain information on health matters, both generally, and, specifically, with respect to a pandemic influenza. As described in chapter two, a core element of Australia's health plan for dealing with a pandemic (AHMPPI), as well as part of the global WHO strategies, has been provision of relevant, timely, evidence-based and appropriately communicated information to the public. The AHMPPI recommends that during a pandemic, the Department of Health and Aging should deliver information to the public on (1) the nature of the respiratory disease, including symptoms and severity, and (2) infection control strategies and how to prepare for the pandemic, with a focus on what people can do themselves to minimize the potential negative impact on their lives, and on the wellbeing of others in the community (i.e. reducing the risk of infection to the individual and contributing to the control of spread to others). As described in chapter two, this could include increased hand washing, wearing a face mask, isolating oneself at home, or having a vaccination (although this is likely not to be available in the early states of the pandemic).

Information received about a health threat, and the level of trust invested in the source reporting the threat, influences a person's perceived risk of the threat and associated affective response. Risk perception and affective response, in turn, influence willingness to adopt protective measures and related health behaviours, which impact on health outcomes.

This component of the study broadly explores the amount of health information people with schizophrenia report obtaining from various sources, and the level of trust invested in those sources, compared with people in the general population. Results are presented and discussed, followed by commentary on limitations and practical implications.

5.1.2 Between-group analysis

As shown in Table 5.1.1, the most commonly used sources for obtaining a substantial amount of information on health matters for participants in the SCZ group were, in rank order, doctor, family and friends, and television. More than 50% of people in the SCZ group reported obtaining at least a moderate amount of information from each of these sources. By comparison, in the GP group most health information was derived from, in rank order, a doctor, the Internet, and family and friends. Approximately 60% of participants with schizophrenia reported obtaining at least a moderate amount of information from a doctor compared with about 80% of people in the GP group. Only 35.2% of people in the SCZ group reported using the Internet as a substantial

Table 5.1.1 Comparison between SCZ and GP groups in obtaining at least a moderate amount of health information from a given source

	SCZ (%) (n=71)	GP (%) (n=238)	OR (95% CI)	*p*	AOR (95% CI)	*p*
Doctor	59.2	80.7	0.35 (0.20-0.61)	**< 0.01***	0.27 (0.12-0.60)	**< 0.01***
Internet	35.2	66.5	0.27 (0.24-0.72)	**< 0.01***	0.43 (0.22-0.88)	**0.02***
Family & Friends	53.5	58.4	0.82 (0.48-1.40)	0.47	0.74 (0.37-1.49)	0.41
Television	52.1	34.0	2.11 (1.23-3.61)	**0.01***	1.51 (0.78-2.96)	0.23
Radio	37.1	20.6	2.28 (1.30-4.06)	**0.01***	1.58 (0.75-3.31)	0.23
Newspaper	19.7	29.1	0.60 (0.31-1.14)	0.12	0.61 (0.27-1.35)	0.22
Magazine	25.4	23.9	1.10 (0.59-1.99)	0.81	1.45 (0.67-3.15)	0.35

* statistical significance ($p < 0.05$); OR, odds ratio; AOR, adjusted odds ratio (adjusted for age, gender, living alone, socio-economic status, children in household, and non-English language spoken at home); CI, confidence interval; SCZ, schizophrenia; GP, general practice

source of health information compared with 66.5% of participants in the GP group. Mann-Whitney U tests (Table 5.1.2) indicate statistically significant differences between SCZ and GP groups in the amount of health information

Table 5.1.2 Differences between SCZ and GP groups in amount of health information obtained from, and level of trust in, a given source

Amount of health information

	Mann Whitney U	z	r	Mean rank		Median Value		p
				Scz	GP	Scz	GP	
Doctor	6201.5	- 3.548	0.20	123.4	164.4	3	4	**< 0.01***
Internet	5578.5	- 4.397	0.25	114.6	165.9	2	3	**< 0.01***
Television	6584.5	- 2.980	0.17	181.3	147.2	3	2	**< 0.01***
Radio	6292.0	- 3.310	0.19	183.6	145.9	2	2	**< 0.01***
Newspaper	7774.0	- 1.032	0.06	145.5	157.2	2	2	0.30
Magazine	8272.0	- 0.285	0.02	157.5	154.3	2	2	0.61
Family & Friends	8316.0	- 0.211	0.01	153.1	155.6	3	3	0.83

Level of trust

	Mann Whitney U	z	r	Mean rank		Median Value		p
				Scz	GP	Scz	GP	
Doctor	5364.5	- 5.042	0.29	111.6	168.0	4	4	**< 0.01***
Internet	6226.5	- 3.496	0.20	123.7	164.3	2	3	**< 0.01***
Television	7378.5	- 1.729	0.10	170.1	150.5	2	2	0.08
Radio	7296.0	- 1.839	0.10	171.2	150.2	2	2	0.06
Newspaper	7929.5	- 0.830	0.05	147.7	157.2	2	2	0.41
Magazine	7979.5	- 0.509	0.03	149.5	155.3	2	2	0.61
Family & Friends	7969.0	- 0.576	0.03	149.3	156.0	3	3	0.57

* statistical significance ($p < 0.05$); Cohen criteria for r values: 0.1 = small effect; 0.3 = medium effect; 0.5 = large effect;

SCZ, schizophrenia; GP, general practice

Table 5.1.3 Comparison between SCZ and GP groups in at least a moderate amount of trust in a given health information source

	SCZ (%) (n=71)	GP (%) (n=238)	OR (95% CI)	p	AOR (95% CI)	p
Doctor	77.5	96.2	0.14 (0.06-0.32)	**< 0.01***	**0.22 (0.06-0.74)**	**0.01***
Internet	35.2	56.7	0.42 (0.24-0.72)	**< 0.01***	0.63 (0.32-1.26)	0.13
Family & Friends	62.9	67.2	0.83 (0.47-1.44)	0.50	1.02 (0.50-2.08)	0.46
Television	42.3	35.3	1.34 (0.78-2.30)	0.29	1.15 (0.59-2.26)	0.68
Radio	36.6	34.5	1.10 (0.63-1.91)	0.74	1.01 (0.51-2.03)	0.97
Newspaper	35.2	39.9	0.82 (0.47-1.42)	0.48	1.06 (0.64-2.72)	0.87
Magazine	30.0	31.2	0.94 (0.53-1.69)	0.85	1.32 (0.61-2.21)	0.46

* statistical significance ($p < 0.05$); OR, odds ratio; AOR, adjusted odds ratio (adjusted for age, gender, living alone, socio-economic status, children in household, and non-English language spoken at home); CI, confidence interval; SCZ, schizophrenia; GP, general practice

obtained from a doctor, the Internet, television and radio. With respect to trust there were statistically significant differences between the two groups for doctor and the Internet. As shown in Table 5.1.1, regression analyses crude scores reflect these Mann-Whitney U test findings. However, when results are adjusted for potential confounders (i.e. adjusted odds ratios) the differences remain only for amount of information obtained from a doctor and the Internet,

Table 5.1.4 Between-group differences in amount of information obtained from, and trust in, information sources, using Likert scale means (independent-samples t-test and Levene's test for homogeneity of variance)

Amount of health information obtained

	Mean		t	p	Eta squared	Levene's test	
						F	p
	SCZ (n=71)	GP (n=238)					
Doctor	2.89	3.41	3.79	**0.01***	0.05	0.24	0.63
Internet	2.20	2.90	4.49	**< 0.01***	0.06	0.63	0.43
Television	2.68	2.22	-3.08	**< 0.01***	0.04	11.42	< 0.01*
Radio	2.31	1.80	-3.41	**< 0.01***	0.05	11.39	< 0.01*
Newspaper	2.01	2.06	0.36	0.72	< 0.01	0.15	0.70
Magazine	2.04	1.97	-0.54	0.59	< 0.01	0.78	0.38
Family / Friends	2.76	2.78	0.12	0.90	< 0.01	0.86	0.36

Level of trust

	Mean		t	p	Eta squared	Levene's test	
						F	p
	SCZ (n=71)	GP (n=238)					
Doctor	3.38	4.09	5.03	**< 0.01***	0.11	24.21	< 0.01*
Internet	2.24	2.72	3.44	**< 0.01***	0.04	3.09	0.08
Television	2.48	2.22	-2.09	**0.04***	0.01	3.15	0.08
Radio	2.44	2.13	-2.40	**0.02***	0.02	3.70	0.06
Newspaper	2.27	2.32	0.44	0.66	< 0.01	3.76	0.05
Magazine	2.11	2.10	-0.09	0.93	< 0.01	6.85	0.01*
Family / Friends	2.86	2.94	0.62	0.54	< 0.01	0.82	0.37

* statistical significance ($p < 0.05$); SCZ, schizophrenia; GP, general practice; Cohen's criteria for eta squared: 0.01 = small effect; 0.06 = moderate effect; 0.14 = large effect

and for trust in a doctor. People with schizophrenia were only about a quarter as likely (AOR = 0.27, 95% CI = 0.12-0.60, $p < 0.01$) to obtain at least a moderate amount of information from their doctor compared to the GP group, and less than half as likely (AOR = 0.43, 95% CI = 0.22-0.88, $p = 0.02$) to access at least a moderate amount of health information from the Internet. Compared with adults in the GP group, people with schizophrenia were significantly less likely to trust their doctor (AOR = 0.22, 95% CI = 0.06 - 0.74, $p = 0.01$) (Table 5.1.3). Similar between-group differences were found using an independent samples t-test to examine Likert scale means (Table 5.1.4). The same four information sources as found in the Mann-Whitney U test (doctor, Internet, television and radio) were identified as differences in obtaining at least a moderate amount of health information. In terms of trust, television and radio were also identified as between-group differences in addition to doctor and the Internet (revealed in the Mann-Whitney U test), reflecting greater sensitivity of the parametric test. Homogeneity of variance (i.e. $p > 0.05$ in the Levene's test) was present for all statistically significant responses, except television and radio, in *amount of health information obtained*, and except for doctor in *trust in information sources*.

5.1.3 Within-group analysis

Results of the within-group logistic regression analyses are shown in Table 5.1.5 and Appendix 9. Information sources in each group (SCZ, GP) were examined one at a time for *socio-demographic predictors* of: (1) at least a

Table 5.1.5 Socio-demographic variables as predictors of a substantive amount of health information gained from, or trust invested in, health information sources: within-group multiple logistic regression

Predictor	SCZ (n=71)			GP (n=238)		
	Outcome	Exp(B)	p	Outcome	Exp (B)	p
Age	ns	-	-	Information from doctor	1.03	0.01
				Information from family/friends	0.97	0.01
				Trust in family/friends	0.97	0.01
Gender (male)	Trust in family/friends	0.15	0.01	Information from doctor	0.47	0.03
Employed	ns	-	-	Information from newspaper	0.43	0.03
				Trust in doctor	4.84	0.03
Living alone	Information from TV	4.42	0.01	Trust in radio	2.27	0.04
Highest level of education	Trust in Internet	n/a	0.03	Information from doctor	n/a	0.03
				Information from Internet	n/a	0.01
Household income	ns	-	-	Information from radio	n/a	0.01
Children in the household	ns	-	-	Information from magazines	2.53	0.01
Non-English language spoken at home	ns	-	-	Information from magazines	2.60	0.01
				Information from family/friends	2.48	0.02

Only statistically significant ($p < 0.05$) results shown (see Appendix 9 for all results); ns, nil significant i.e. socio-demographic variable did not predict a substantive amount of health information gained from, or trust invested in, any of the health information sources (to statistical significance); Exp(B), exponential of regression coefficient B; n/a, not applicable as *highest level of education* and *household income* are categorical variables with 4 degrees of freedom; SCZ, schizophrenia; GP, general practice

moderate amount of information obtained from a given information source, and (2) at least a moderate level of trust in a given information source.

Gender

Gender was found to be a significant predictor of (1) trust in family and friends as a health information source, in the SCZ group, and (2) amount of health information obtained from a doctor, in the GP group. Men with schizophrenia were approximately seven times less likely than women with schizophrenia to substantively trust family and friends as providers of health information. In the GP group, women were two and a half times more likely than men to obtain a substantive amount of health information from a doctor.

Employment status

Employment status was not a statistically significant predictor for amount of information obtained from, or trust in, any of the information sources in the SCZ group. In the GP group, it was a statistically significant predictor for amount of health information obtained from newspapers, and trust in doctors. Compared with those not working, people in employment were less than half as likely to obtain at least a moderate amount of health information from newspapers ($p = 0.03$, Exp(B) = 0.43) and close to five times more likely to have substantive levels of trust in a doctor as an information source ($p = 0.03$, Exp(B) = 4.84).

Living alone

Living alone was a statistically significant predictor of amount of information obtained from television in the SCZ group. People who lived by themselves were about four and a half times more likely to obtain an at least moderate amount of health information from television, compared with those who did not live alone (p = 0.01, Exp(B) = 4.42). In the GP group, those who lived alone were about two and a quarter times more likely to trust radio as a health information source compared with those who did not live alone (p = 0.04, Exp(B) = 2.27).

Education

Highest level of education (as an "overall" variable with four degrees of freedom) was found to be a significant predictor of (1) trust in the Internet as a health information source, in the SCZ group, and (2) amount of health information obtained from a doctor, and from the Internet, in the GP group. Using *university degree* as the reference group, and the other levels of educational attainment as "dummy" variables (with one degree of freedom), it was found that having a *university degree* increased the likelihood of at least a moderate level of trust in the Internet as a health information source, 48-fold compared to no educational attainment (p = 0.04, Exp(B) = 0.021), and 71-fold compared to *Year 10 certificate* only (p = 0.02, Exp(B) = 0.014)*,* for people with schizophrenia. For people in the GP group, having only a *Year 10 certificate* made it 27 times more likely to obtain a substantive amount of health information from a doctor compared to those with no educational attainment

(p = 0.04, Exp(B) = 27.35), and 28 times more likely for those whose highest

educational attainment was a *Year 12 certificate* compared to those with no

educational attainment (p = 0.03, Exp(B) = 27.59). People in the GP group who

had a *university degree* were over four and a half times more likely to obtain an

at least moderate amount of health information from the Internet compared

with those with only a *Year 12 certificate* ($p < 0.01$, Exp(B) = 4.76).

Household income

Income was not a statistically significant predictor for amount of information

obtained from, or trust in, any of the information sources in the SCZ group. In

the GP group, estimated household income, as an "overall" variable with four

degrees of freedom, was a statistically significant predictor of amount of

information obtained from radio (p = 0.01). Using dummy variables, each with

one degree of freedom, it was revealed that participants living in households

with an estimated annual income of $20,000 - 40,000 were five times more

likely to obtain a substantive amount of health information from radio compared

with people living in household with an estimated annual income of more than

$80,000 ($p$ = 0.01, Exp(B) = 5.10).

Children in the household

The presence of children in the household was not a statistically significant

predictor for amount of information obtained from, or trust in, any the

information sources for the SCZ group. In the GP group, those with children in

the household were two and a half times more likely to obtain a substantive amount of information from magazines ($p = 0.01$, Exp(B) = 2.53).

Non-English language(s) spoken at home

Languages other than English being spoken in the home was not a statistically significant predictor for amount of information obtained from, or trust in, any of the information sources in the SCZ group. However, in the GP group, participants who lived in a household where a non-English language was spoken were approximately two and a half times more likely to obtain a substantive amount of health information from family and friends ($p = 0.02$, Exp(B) = 2.48) and from magazines ($p = 0.01$, Exp(B) = 2.60), compared with those living in homes where only English was spoken.

Age

Age was not a statistically significant predictor for amount of information obtained from, or trust in, any of the information sources in the SCZ group (despite mostly ample power). In the GP group, age was a statistically significant predictor of amount of information obtained from a doctor ($p = 0.01$, Exp(B) = 1.03), and family and friends ($p = 0.01$, Exp(B) = 0.97), and for trust in family and friends ($p = 0.01$, Exp(B) = 0.97). However, with the odds ratios equal to 1.0 (correct to one decimal place) it did not have "real world" or clinical significance.

Correlation between use and trust in information sources

In both groups there was a statistically significant positive correlation (Table 5.1.6) between the amount of information obtained from a given source and the level of trust invested in it, except for newspaper in the schizophrenia group.

Table 5.1.6 Spearman's correlations between amount of health information obtained from, and level of trust in, a given source

	SCZ (n = 71)		GP (n = 238)	
	rho	p	rho	p
Doctor	0.53	< 0.001*	0.51	< 0.001*
Internet	0.60	< 0.001*	0.64	< 0.001*
Television	0.37	0.001*	0.61	< 0.001*
Radio	0.50	< 0.001*	0.60	< 0.001*
Newspaper	0.21	0.081	0.50	< 0.001*
Family & Friends	0.52	< 0.001*	0.70	< 0.001*
Magazines	0.50	< 0.001*	0.63	< 0.001*

* statistical significance ($p < 0.05$); SCZ, schizophrenia; GP, general practice; rho, Spearman's Rank Order Correlation

5.1.4 Discussion

Use of health information sources

People with schizophrenia are exposed to health threats arising from both their significant vulnerability to comorbid medical disorders, including influenza during a pandemic, as well as risks and challenges associated with their mental illness. Therefore, the disparity between the SCZ and GP groups in the use of doctors and the Internet as health information sources, revealed in this thesis study, is of concern. People suffering from schizophrenia need to be able to receive relevant and optimally communicated information from their doctor(s) about their health generally as well as specific health threats such as pandemic influenza, especially if they have developed symptoms or have had exposure to someone who has. However, significant challenges exist. One important limiting factor for receiving health information from doctors is a shortage of general practitioners in some regions (Thistlethwaite et al. 2008). With respect to the thesis study, the Australian Capital Territory has the lowest general practitioner bulk billing rate of any state or territory in Australia, as well as a relative shortage of general practitioners (Australian Government, Medicare 2009). This is particularly relevant given that a large majority of participants in the SCZ group in this study reported an estimated annual household income of less than $20,000.

There has been an expansion of the Internet as an accessible, dynamic and interactive information source for mental and physical health issues (Christensen & Griffiths 2000). Furthermore, the Internet has been

promulgated as enhancing mental health literacy and promoting engagement in mental heath programmes, especially for those who do not feel comfortable seeking, or who cannot access (e.g. due to rural or remote locations), face-to-face professional help (Christensen & Griffiths 2000). Close to two thirds of respondents in the general population of the United States have reported using the Internet for any reason, and health information seeking was by far the most commonly reported online activity (Hesse et al. 2005). In contrast, the finding in the thesis study of the relative lack of use of the Internet for acquiring health information by people with schizophrenia places them at a potential disadvantage. Although it seems plausible that higher level of education might be correlated with use of the Internet as a source of health information, this was only the case for the GP group, a finding consistent with prior research (Hesse et al. 2005; Dart et al. 2008). Seeking to understand the barriers and facilitators to accessing the Internet for people with schizophrenia remains an important endeavour.

Trust in information sources

There was a comparatively lower level of trust in 'doctor' as health information sources by participants with schizophrenia, compared with volunteers in the GP group. Trust has long been recognized as a core element of the therapeutic relationship between a doctor and a patient (Peabody 1927; Parsons 1951; Mechanic 1996; Kao et al. 1998) and is a significant contributor to therapeutic outcomes (Musa et al. 2009). For example, low levels of patient trust in their doctor have been shown to be associated with poor perceived

effectiveness of care, reduced adherence to management recommendations, less doctor-patient contact and poorer continuity of care, less utilization of health care services, greater likelihood of seeking a second opinion and worse health by self-report (Safran et al. 1998; Thom et al. 1999; Hall et al. 2001; O'Malley et al. 2004; Thom et al. 2004). Unfortunately, however, there has been a lack of successful interventions that have been measurably shown to significantly improve trust by patients towards their doctors (Pearson & Raeke 2000). Given the persecutory ideation, guardedness, asociality and other negative symptoms experienced by many people with schizophrenia, the challenges in developing robust levels of trust in the clinician-patient relationship are considerable. As mentioned in the chapter on methodology, the concept of "doctor" or "your doctor" is subjective with respect to whom it specifically refers to, especially in mental health services in the public sector. There may exist a range of medical clinicians who participate in the care of a patient, including treating psychiatrist, general practitioner employed by mental health services (not part of mental health services in the ACT at the time of the present study) or private general practitioner, and medical specialist (consulted in the context of medical comorbidity). In addition, some patients with a mental illness might view their psychologist with a Doctor of Philosophy degree (PhD), who has a title of 'Doctor', as "your doctor". Therefore, this category of information source is heterogeneous.

In the thesis study, the proportion of participants in the SCZ group who reported placing at least a moderate amount of trust in the Internet was only

about half that of the GP group (35.2% versus 66.5%). The Internet was also lower in the rank order of at least moderately trusted sources in the SCZ group. The Mann-Whitney U Test, and t-test, found a statistically significant difference between the two groups, with more trust invested in the Internet by participants in the GP group. However, when potential confounders were adjusted for in the regression analysis, this difference did not reach statistical significance.

Perhaps there is justification and, indeed, merit, in having a *degree* of reservation regarding the level of trust placed in the Internet as a health information source. For example, a study evaluating 21 popular websites on depression (Christensen & Griffiths 2000) found that their overall quality was poor due to misinformation, misleading information and a lack of balance. The authors highlighted a need for quality assurance mechanisms and suggested the possibility of developing intelligent search engines that use algorithms linked to 'gold standards'. Finally, while fully utilizing the technical advances of electronic health resources such as the Internet to enhance outreach and delivery of mental health care, it is important also to ensure that the humanity and sense of value of patients be supported and not replaced (Looi & Raphael 2007). Qualities such as respect, warmth, cultural sensitivity, and the communication of a desire to understand and help, which are an accepted part of face-to-face contact with patients, need also to be present in electronic health care delivery.

Correlation between amount of information obtained from and level of trust in a given information source

In the present study, a significant amount of the variance in the quantity of information obtained from a given source (in both groups) was explained by variation in the level of trust invested in that source (Table 5.1.6). This was especially so for family and friends in the GP group ($r^2 = 0.49$). It makes intuitive sense that if an information source is trusted it is more likely to be used, and conversely, that if a source is used and found to be reliable, it is likely it will become trusted. However, this correlation is not always the case. A study of 810 college students aged 18-24 (LaJoie & Ridner 2009) found that these young people reported obtaining most of their health information from sources they did not particularly trust, such as friends, the media, and the Internet. On the contrary, although health professionals were highly trusted by these students, they were among the least common providers of health information. Furthermore, as described in the chapter two, another study (Hesse et al. 2005) revealed that although physicians remained the most highly trusted source, and respondents reported *wanting* to access them first to obtain specific health information, when asked what they actually *did*, almost 50% reported going online first compared with 10.9% who indicated consulting their physician first.

Socio-demographic variables as predictors of use of and trust in information sources

Socio-demographic group differences between participants with schizophrenia and people attending a general practice reflect a tendency for people with schizophrenia to have less social connectivity and lower socio-economic status than those in the general population. There was a relatively higher proportion of participants with schizophrenia living alone, unemployed, having a lower educational attainment, living in a lower income household, and not having children in the household. Several of these socio-demographic characteristics were also within-group predictors of a substantive amount of information obtained from, or level of trust in, a given information source. There were more statistically significant socio-demographic predictors for the GP group, which may reflect the greater power enabled by the higher number of participants (n = 238 versus n = 71) but also the greater socio-demographic diversity within this group. For instance, in the SCZ group 70% of participants lived in household earning less than $20,000 per year, whereas in the GP group household incomes were more varied.

For the SCZ group, significant positive predictors were *higher level of education* (greater likelihood to trust the Internet), *gender* (greater likelihood of women to trust family and friends) and *living alone* (greater likelihood to obtain health information from television). For the GP group, significant predictors included gender (greater likelihood of women to obtain health information from doctors), higher *education* (greater likelihood to obtain information from a

doctor or the Internet), *being employed* (greater likelihood of trusting a doctor, and lower likelihood to gain health information from newspapers), higher *household income* (lower likelihood to obtain health information from radio), *children in the household* (greater likelihood to gain health information from magazines), and *non-English language spoken at home* (greater likelihood to obtain health information from magazines and from family and friends, perhaps reflecting closer family ties in ethnic communities).

5.1.5 Limitations

General limitations of the research project will be discussed in the final chapter. However, there are several limitations specific to this part of the thesis study. The level of educational attainment is disproportionately high in the Australian Capital Territory. Based on 2009 Australian Bureau of Statistics (2009) data, 34.9% of persons aged 15-64 years in the Australian Capital Territory have a bachelor or post-graduate university degree compared with 23.0% in Victoria, 22.7% in New South Wales (the two states ranked next) and 20.5% for Australia as a whole. This disparity in educational attainment presents difficulties in generalizing the results from the present study to other states or territory. A further limitation is that the information sources section of the thesis questionnaire used the term doctor generically without identifying whether it was referring to the participant's psychiatrist, general practitioner, a medical practitioner in some other field of medicine, a psychologist, or a combination of these. In addition, there were no data gathered on the frequency of contact with the doctor or the nature of service provided.

Participants with schizophrenia may have had less contact (than those attending a general practice) with medical practitioners both within and outside public mental health services. The thesis study did not distinguish between passively acquiring health information (e.g. while reading a newspaper), and actively seeking specific information (e.g. after experiencing cough and fever); however, the candidate was interested in both in this early phase of research into this area and did not add such detail in order to avoid overburdening the survey participants. Furthermore, the study did not specify the type of health information sought or explore the subgroups within a given information source e.g. different genres of magazines. Finally, given the differences in the amount of health information gained from the Internet between people with schizophrenia and those in the general population, it would have been interesting to know what level of access to online resources each group had, especially in light of the disparities in socio-economic status between the two groups.

5.1.6 Practical Implications

Important practical implications arise from this part of the study. The findings suggest a need for investigation into strategies that enable stronger and more effective communication links between patients with schizophrenia and their clinicians. Relevant and evidence-based health information may need to be provided by a range of health professionals not solely the general practitioner. For instance, it may be beneficial for psychiatrists and mental health nurses to take a more active role in providing important physical health information, as

they may have the most contact with the patient. Regardless of which health professional is involved, it seems important that an assertive approach is adopted. An active enquiry about health issues generally is likely to be the most effective approach, as well as the provision of information on potential health threats, such as an emerging pandemic influenza. It may be disadvantageous to patients with schizophrenia for clinicians to have an expectation that physical symptoms or concerns will be disclosed spontaneously. Health information about preventative measures, not only against influenza but also against medical disorders people with schizophrenia are prone to, such as ischaemic heart disease, chronic obstructive pulmonary disease and diabetes mellitus, is important.

As family and friends ranked both the second most trusted and second most used source for people with schizophrenia to gain health information (and the second most trusted and third most used in the GP group), clinicians might consider encouraging and supporting them as contributors to the provision of health information, as is the case in many chronic neurodegenerative diseases. This might include provision of information sheets and pamphlets that they could share with the patient at a later time.

As information and communications technologies continue to improve and expand, e-health is likely to play an increasingly important role in the future in our society. Therefore, the finding in the present study suggesting under-utilization of online health information sources warrants further investigation.

Research seeking to understand how people with schizophrenia view the Internet in general as well as Internet-based health information and online health services, specifically, is likely to be useful. Assistance with education and skills to use computers and other electronic devices such as 'smart phones' and 'tablets', is also likely to be helpful, given the lower levels of educational attainment found in this study. Educational resources may also enhance levels of trust in the Internet, given the finding in the present study that a higher level of education made it significantly more likely that a person with schizophrenia would trust the Internet as a health information source. As low socio-economic status may negatively impact on the opportunity to purchase or rent a computer or other electronic device, providing free Internet access for people with schizophrenia in community settings such as 'drop-in centres', may enhance the use of the Internet for acquiring health information. Hospital admissions may also provide an opportunity to explore what assistance or special provisions individuals with schizophrenia may require if accessing hospital information technology services. The development of community health programmes which utilize electronic resources but which have strong links to treating clinicians, including psychiatrists and general practitioners, is potentially an effective approach (Dart et al. 2008). These clinicians could have a role in identifying which particular community programmes have the most relevance for their patients. For people with schizophrenia this might include electronic educative resources (e.g. specific 'apps') which promote healthy life style choices and, if applicable, advice on how to quit smoking, as well as preventative strategies against a range of

preventable diseases. In the event of an emerging influenza pandemic, this might include e-health messages and advice on protective measures, including improved hand hygiene as a simple but effective action as promoted by the National Hand Hygiene Initiative discussed in chapter two.

5.1.7 Conclusion

There exist significant differences in the reported utilization and trust of health information sources between people with schizophrenia attending mental health care settings, and the general public, especially with respect to doctors and the Internet. People with schizophrenia are less likely to trust and access health information from their doctor, and less likely to access the Internet for health information. While there are many potential factors that might contribute to this, these findings highlight the need for effective management initiatives and social inclusion, especially when facing the threat of an influenza pandemic, building on requirements for optimal health more broadly. Given the likelihood of the Internet playing an increasingly dynamic role in health information and service delivery in the future, and also the importance of accessing and discussing health advice from medical practitioners, further research may be required to inform on strategies to enhance accessing and trusting these information sources. This is particularly critical in light of the vulnerability of people with schizophrenia during an influenza pandemic as well as more generally, given their high rates of medical comorbidity and mortality, compared with the general population.

5.2 Risk perception of pandemic influenza

5.2.1 Introduction

The H1N109 outbreak provided a unique opportunity to gain valuable insights into how people with schizophrenia and people attending a general practice perceived risk *during* a pandemic influenza. As described in chapter four, the survey was launched three weeks after swine flu was declared a global pandemic by the WHO, and was continued for four months. Results of the risk perception aspect of the study are presented and discussed, followed by commentary on limitations and practical implications.

5.2.2 Between-group analysis

In both groups, a little over half of the participants (SCZ = 54.9%, GP = 56.7%) reported perceiving a substantive (i.e. moderate, high or extreme) risk from swine flu (Table 5.2.1). In the SCZ group, 37.1% of participants believed they were at least moderately likely to contract swine flu compared with 52.6% in the GP group. However, only 15.5% in the SCZ group perceived their risk of becoming infected as *very or extremely* high, compared with 22.8% in the GP group. Over half of the participants in each group (SCZ = 63.2%, GP = 54.2%) believed it would be serious if they contracted H1N109 and a little under two thirds in each group reported believing they could avoid contracting swine flu. In the SCZ group, 33.8% believed it would be *very or extremely* serious if they contracted the virus, as did 24.4% in the GP group. Compared with the GP group, a higher proportion of participants with schizophrenia felt vulnerable in

knowing there was a current global influenza pandemic (44.1% versus 32.0%). Similarly, a greater proportion of participants in the SCZ group predicted they would feel afraid (47.9% versus 36.1%) or depressed (32.4% versus 20.2%) if they contracted swine flu, compared with the GP group. There was poorer knowledge of pandemic influenza and a higher proportion of people perceiving death as a likely outcome in the SCZ group, compared with the GP group. Only about 14% of the SCZ group (compared with 32.5% in the GP group) was able to name three symptoms of influenza and demonstrate knowledge of the duration of the disease. Approximately 40% of the SCZ group thought that death was at least a moderately likely consequence of contracting swine flu, compared with 23.8% in the GP group. Chi-square tests (Table 5.2.1) revealed no statistically significant differences between the groups for core risk perception dimensions but found significant differences for predicted depressed feelings if swine flu were contracted, factual knowledge of influenza, and death perceived as an at least moderately likely consequence of contracting H1N109. Parametric analysis using t-tests (Table 5.2.2) to examine for differences in the means of Likert scores showed a difference of small effect size between the groups for *perceived likelihood* of contracting swine flu (t = 2.66, eta squared = 0.02, *p* = 0.01*)*. Homogeneity of variance was present in of all these t-tests. Logistic regression analysis crude scores (Table 5.2.1) mirrored these between-group differences found in the Chi-square and t-test. However, adjusted odds ratios showed statistically significant differences between the two groups only for knowledge of the disease (less knowledge in SCZ group). Adjustments were made for age, gender, socio-economic status,

Table 5.2.1 Comparison between SCZ and GP groups for swine influenza risk perception variables (self-reporting of at least a moderate level of each item) and factual knowledge

	SCZ (%) (n=71)	GP (%) (n=238)	χ^2, df, p value	OR (95% CI)	p	AOR (95% CI)	p
Overall risk to self	54.9	56.7	3.80, 4, 0.43	0.97 (0.58-1.63)	0.92	0.95 (0.51-1.79)	0.88
Own likelihood of contracting	37.1	52.6	9.72, 4, 0.05	**0.56 (0.33-0.95)**	**0.03***	0.68 (0.35-1.32)	0.26
Seriousness of contracting	63.2	54.2	4.44, 4, 0.35	1.33 (0.77-2.29)	0.30	1.30 (0.66-2.56)	0.45
Control (able to avoid contracting)	63.6	63.4	5.12, 4, 0.40	0.99 (0.57-1.73)	0.97	0.89 (0.46-1.76)	0.75
Feeling vulnerable	44.1	32.0	7.33, 4, 0.12	1.49 (0.87-2.54)	0.14	1.53 (0.77-3.03)	0.23
Affective response: Afraid	47.9	36.1	8.67, 4, 0.07	1.36 (0.81-2.28)	0.25	1.30 (0.67-2.51)	0.21
Affective response: Depressed	32.4	20.2	11.01, 4, **0.03***	**1.90 (0.70-32.12)**	**0.03***	0.88 (0.43-1.80)	0.72
Outcome death	40.9	23.8	13.32, 4, **0.02***	**1.91 (1.10-3.32)**	**0.02***	1.14 (0.56-2.33)	0.73
Factual knowledge of the disease	13.8	32.5	5.75$^\$$, 1, **0.02***	**0.37 (0.17-0.81)**	**0.01***	**0.40 (0.16-0.96)**	**0.04***

* statistical significance ($p < 0.05$); $^\$$ Yates continuity correction used; χ^2, chi-square; df, degrees of freedom; OR, odds ratio; AOR, adjusted odds ratio (adjusted for age, gender, socio-economic status, living alone, non-English language spoken at home, knowledge of influenza experience, general self-rated health, Kessler 10 total score, and week of participation); SCZ, schizophrenia; GP, general practice

Table 5.2.2 Between-group differences in core risk perception dimensions using Likert scale means (independent-samples t-test and Levene's test for homogeneity of variance)

	Mean		t	p	Eta squared	Levene's Test	
	SCZ (n=71)	GP (n=238)				F	p
Overall risk	2.79	2.75	-0.32	0.75	< 0.01	0.16	0.69
Likelihood of self contracting swine flu	2.34	2.75	2.66	**0.01***	0.02	0.23	0.63
Seriousness of self contracting swine flu	3.01	2.73	-1.80	0.07	0.01	0.67	0.41
Feeling vulnerable	2.54	2.26	-1.91	0.06	0.01	0.29	0.59

* statistical significance ($p < 0.05$); Cohen's criteria for eta squared: 0.01 = small effect, 0.06 = medium effect, 0.14 = large effect; SCZ, schizophrenia; GP, general practice

living alone, non-English language spoke at home, knowledge of influenza experience, general self-rated health, Kessler 10 scores, and week of participation in the study, as these variables were considered likely to impact on risk perception.

5.2.3 Within-group analysis

Results of the within-group logistic regression analyses are shown in Table 5.2.3. A Cronbach alpha of 0.7 for the matrix of items chosen as dimensions and potential determinants of *perceived overall risk* to self from swine flu during the pandemic suggested an acceptable level of internal consistency.

Table 5.2.3 Predictors of perceived substantive overall risk to self from swine flu if no protective measures taken: within-group multiple logistic regression

Predictor variable	SCZ (n=71)		GP (n=238)	
	Exp (B)	p	Exp (B)	p
Age	1.02	0.70	1.01	0.25
Gender (= male)	0.47	0.47	1.01	0.97
Highest level of education	-	0.30	-	0.05
Lives alone	2.93	0.22	1.45	0.47
Employed	3.98	0.22	1.62	0.19
Perceived likelihood of self contracting swine flu	**5.66**	**< 0.01***	**2.13**	**< 0.01***
Perceived seriousness of contracting swine flu	**5.12**	**< 0.01***	1.04	0.81
Perceived vulnerability to global pandemic	0.45	0.09	0.78	0.20
Affective response: afraid	**5.14**	**0.04***	1.52	0.07
Affective response: depressed	**0.29**	**0.04***	1.12	0.60
Knowledge of influenza experience	1.13	0.90	1.00	0.99
Perceived likelihood of death	1.21	0.55	**1.37**	**0.03***
General self-rated health	**0.16**	**0.02***	0.72	0.11
K10 total score	**0.79**	**0.02***	0.99	0.53
K10 anxiety subscale score[#]	**0.44**	**0.01***	1.06	0.50
K10 depression subscale score[#]	0.83	0.14	0.95	0.28
K10 total score ≥ 20[#]	**0.06**	**0.03***	0.81	0.55

* statistical significance ($p < 0.05$); Exp(B), exponential of regression coefficient B; K10, 10-item Kessler Psychological Distress Scale; # replaces K10 total score as predictor variable; SCZ, schizophrenia; GP, general practice

In the SCZ group, positive predictors of a perception of substantive overall risk to self from swine flu were *perceived likelihood* and *perceived seriousness* of contracting swine flu, as well as a prediction of feeling afraid in the event of contracting swine flu in the future. Factors associated with a reduced likelihood of perceived substantive overall risk to self from swine flu included: a predicted affective response of depressed mood if swine flu were contracted in the

future; favourable self-rated health; a higher K10 total score; a higher K10 anxiety subscales score; and a K10 total score ≥ 20, versus < 20 (Table 5.2.3). For the GP group, predictors of perceived substantive risk from swine flu were *perceived likelihood* of contracting swine flu and *perceived likelihood of death* as a consequence of contracting swine flu (Table 5.2.3). None of the K10 parameters were predictors of perceived substantive risk from H1N109, for the GP group. The descriptives for the K10 variables are shown in Table 5.2.4, indicating statistically significant differences between the SCZ and GP group for K10 total scores, the K10 anxiety subscale and K10 total score ≥ 20, versus < 20. These findings suggest that participants with schizophrenia experienced greater levels of psychological distress and were more anxious than people in the GP group.

Socio-demographic variables

Within-group risk perception was examined with respect to the socio-demographic variables of *gender*, *education* and *income*, from both an *ecological* (i.e. aggregate level) perspective using frequencies and chi-square test, as well as using an *analytical* (i.e. individual level) approach employing logistic regression.

Gender

In the SCZ group, only a slightly higher proportion of women (57.1%) than men (54.0%) perceived a substantive (i.e. moderate, high or extreme) overall risk to themselves from swine flu. Chi-square test confirmed there was no statistically

Table 5.2.4 K10 variables: descriptives

	SCZ (n = 71)	GP (n = 238)	Statistic[#]
K10 total score			t = -2.88, ***p* < 0.01*** (2-tailed) (F = 1.65, *p* = 0.20)
Mean	21.37	18.60	
SD	7.53	6.98	
Range	30 (10-40)	35 (10-45)	
K10 anxiety subscale score			t = -3.75, ***p* < 0.01*** (2-tailed) (F = 6.27, *p* = 0.01*)
Mean	8.66	7.06	
SD	3.25	2.84	
Range	11 (4-15)	13 (4-17)	
K10 depression subscale score			t = -1.76, *p* = 0.08 (2-tailed) (F = 0.25, *p* = 0.62)
Mean	12.68	11.54	
SD	4.74	4.78	
Range	19 (6-25)	23 (6-29)	
K10 total score ≥ 20			χ^2 = 4.19, ***p* = 0.04***
n (%)	34 (47.9)	80 (33.6)	

* statistical significance (*p* < 0.05)
[#] statistic includes: independent-samples t-test with Levene's test for homogeneity of variance, and Chi-square test; K10, 10-item Kessler Psychological Distress Scale; SD, standard deviation; SCZ, schizophrenia; GP, general practice

significant difference between the genders in terms of perceived overall risk

from swine flu (χ^2 = 0.59, *p* = 0.81) in the SCZ group. Similarly, the proportion

of women in the GP group (59.5%) who perceived a substantive risk from

swine flu was a little higher than for men (51.2%) but with no statistical

significance between the genders demonstrated in the Chi-square test

(χ^2 = 1.47, *p* = 0.23). Therefore, using an ecological approach there was minimal difference between the genders within either group. With an analytical approach using regression analysis, gender was not found to be a statistically significant predictor of perceived risk from swine flu in either the SCZ or GP group (Table 5.2.3). Therefore, at an individual level it was not possible to conclude from the study that a male participant was less likely than a female participant to perceive a moderate, high or extreme overall risk from swine flu within either group.

Education

There were both similarities and differences between the SCZ and GP groups in risk perception with respect to education. In terms of similarities, university-educated people in both groups had a comparable proportion (Table 5.2.5) of those who believed the overall risk from swine flu was substantive (SCZ = 50%, GP = 55.2%). For both groups, the educational level with the lowest risk perception was *None.* In terms of differences, those in the SCZ group with only a *Year 10 certificate* represented the highest proportion (68.2%) of participants with substantive risk perception, in contrast to *TAFE certificate/diploma* for the GP group (76.5%). However, Chi-square tests (5x2) showed no statistically significant differences between the different levels of education for perceived substantive risk from swine flu for either the SCZ group (χ^2 **=** 4.18, *p* = 0.38) or the GP group (χ^2 **=** 7.95, *p* = 0.09). Mirroring these group findings, regression analysis (Table 5.2.3) revealed that highest level of educational

Table 5.2.5 Perceived substantive overall risk from swine flu if no protective measures taken: frequency (%) within levels of education and household income, for SCZ and GP groups

Highest educational attainment			Estimated annual household income		
	SCZ **(n = 71)**	**GP** **(n = 238)**		**SCZ** **(n = 71)**	**GP** **(n = 238)**
None	37.5	25.0	< $20k	59.6	52.2
Year 10 certificate	68.2	50.0	$20-40k	33.3	66.7
Year 12 certificate	61.1	54.4	$40-60k	57.1	54.5
TAFE certificate/diploma	41.2	76.5	$60-80k	50.0	54.5
University degree	50.0	55.2	>$80k	50.0	55.4

attainment was not a significant predictor of perceived overall risk within either group (either as "overall" variable with four degrees of freedom, or for any of the dummy variables, each with one degree of freedom). Therefore, at an individual level it was not possible to conclude from the study that at an individual (in either the SCZ or GP group) with a higher level of educational attainment was more likely than a participant with a lower educational status (in the same group) to perceive a moderate, high or extreme overall risk from swine flu.

Income

Compared with education, there were greater similarities between the SCZ and GP groups in terms of estimated income bracket. Except for the income level $20-40k, proportions in the SCZ and GP groups perceiving a substantive risk

from swine flu were comparable, ranging from 50% and 59.6% (Table 5.2.5). However, for the \$20-40k income bracket, the proportion of people in the GP (66.7%) group was double that of the SCZ group (33.3%) in terms of substantive risk perception. However, again Chi-square tests (5x2) showed no statistically significant differences between the different levels of education for either the SCZ group ($\chi^2 = 2.16$, $p = 0.71$) or the GP group ($\chi^2 = 1.86$, $p = 0.76$). In addition, regression analysis revealed that estimated annual household income was not a significant predictor of perceived risk for either group (either as "overall" variable with four degrees of freedom [$p = 0.55$ SCZ, $p = 0.77$ GP] or for any of the dummy variables, each with one degree of freedom).

5.2.4 Risk perception and socio-economic status

In addition to the within SCZ-GP group approach, pandemic risk perception was also examined more broadly with respect to *gender*, *educational attainment* and *income* within the larger n= 309 sample as a whole. Aggregate level data findings were contrasted with findings at an individual level using regression analysis. Due to the stratified nature of the sample (n = 309) into GP (n = 71) and SCZ (n = 238) groups, the grouping variable (i.e schizophrenia present or not) was retained in the regression model. Risk perception was explored both in terms of perceived *overall risk* from the prevailing swine flu (if no protective measures are taken) as well as its principal dimensions i.e. perceived *likelihood* of (self) contracting swine flu, perceived *seriousness* to self of contracting swine flu, and perceived *vulnerability* from the presence of the swine flu pandemic.

Perceived overall risk from pandemic swine flu

Gender

Aggregate data show a modestly higher proportion of women (59.2%) compared men (52.3%), reporting at least moderate (i.e. moderate, high or extreme) perceived overall risk from the swine flu, if no protective measures were taken (Table 5.2.6). However, Chi-square test did not reveal a statistically significant difference between the genders in this respect ($\chi^2 = 1.46$, $p = 0.23$). In addition, the proportion of women perceiving an extreme risk (7.7%) was close to double than for men (4.6%). The perception of "no risk at all", "a moderate risk" and "a high risk" were all fairly comparable, but a higher proportion of men (41.5%) saw their risk as "small", compared with

Table 5.2.6 Perceived overall risk to self from swine flu if no protective measures taken: frequency (%) by gender (n = 309)

	Male (%)	Female (%)
No risk at all	6.2	5.0
A small risk	41.5	35.8
A moderate risk	36.2	38.5
A high risk	11.5	13.4
An extreme risk	4.6	7.7
No risk at all, or a small risk	47.7	40.8
Moderate, high or extreme risk	52.3	59.2

Table 5.2.7 Perceived substantive overall risk to self from swine flu if no protective measures taken, gender/SES as predictors: logistic regression (n =309)

Predictor variable	B	df	*p* value	Exp(B)$
Gender	- 0.27	1	0.28	0.75
Highest level of education#		4	0.18	
Year 10 Certificate	1.19	1	0.12	3.33
Year 12 Certificate	1.02	1	0.17	2.82
TAFE certificate or diploma	1.67	1	**0.03***	**5.39**
University degree	0.98	1	0.19	2.72
Household income#		4	0.92	
$20-40k	- 0.02	1	0.99	0.99
$40-60k	- 0.13	1	0.81	0.89
$60-80k	- 0.32	1	0.53	0.74
> $80k	- 0.36	1	0.41	0.71

* statistical significance ($p < 0.05$)
$ adjusted for age, employment status, lives alone, children in household, self-rated health, diagnosis of schizophrenia
# coded for by dummy variables with "None" being the reference group for highest level of education, and "< $20k" for household income

women (35.8%). A 5x2 Chi-square test examining for gender differences

across the five possible response options for perceived overall risk (i.e. "no risk

at all" through to "an extreme risk") did not reveal statistical significance (χ^2 = 2.01, p = 0.73).

Despite the differences at the aggregate data level, an analytic approach using logistic regression analysis did not find any statistically significant gender differences (Table 5.2.7). This means that it is not possible to conclude ('ecological fallacy') from the study that at an individual level a male participant was less likely than a female participant to perceive a moderate, high or extreme overall risk from swine flu.

Level of educational attainment

Aggregate data (Table 5.2.8) show similar proportions of people having an at least moderate perceived overall risk from swine flu in those whose highest educational attainment was *Year 10 certificate* (56.9%), *Year 12 certificate* (56.1%) and a *University degree* (54.9%). The proportion of people in the educational attainment group *None* who perceived this level of overall risk was substantively lower (33.3%) than the above groups and the proportion in the *TAFE certificate or diploma* group was higher (64.7%). A 5x2 Chi-square test examining for a difference between educational groups for at least a moderate perceived risk (versus no or only a small perceived risk) from swine flu, did not reveal statistical significance (χ^2 = 4.14, p = 0.39). In all groups with an educational attainment, "a small risk" and "a moderate risk" were the two most frequent responses. However, in the no educational attainment group

Table 5.2.8 Perceived overall risk to self from swine flu if no protective measures taken: frequency (%) by highest educational attainment (n = 309)

	None (%)	Year 10 certificate (%)	Year 12 certificate (%)	TAFE certificate or diploma (%)	University degree (%)
No risk at all	33.3	6.9	3.0	3.9	4.1
A small risk	33.3	36.2	40.9	31.4	41.0
A moderate risk	25.0	36.2	36.4	39.2	39.3
A high risk	0.0	15.5	10.6	15.7	12.3
An extreme risk	8.3	5.2	9.1	9.8	3.3
No risk at all or a small risk	66.7	43.1	43.9	35.3	45.1
Moderate, high or extreme risk	33.3	56.9	56.1	64.7	54.9

although "a small risk" was the most frequent response (33.3%), it was equaled by "no risk at all" (33.3%). The lowest proportion of people reporting an "extreme risk" perception occurred in those with a university degree.

These aggregate data findings may lead to the consideration of a possible hypothesis that poorly educated people are more likely to have a lower risk perception of pandemic influenza, particularly adults with no educational attainments compared to those with a *TAFE certificate or diploma.* Regression analysis (Table 5.2.7) did not find any statistically significance difference for *level of education* as an "overall variable" (*p = 0.18)* with four degrees of freedom, but did with respect to "dummy variables" which coded for this variable in the regression model, representing the different levels of education

(with *None* being the reference group). The adjusted odds ratio for *TAFE certificate or diploma* was 5.39. Therefore, at an individual level, a person with a *TAFE certificate or diploma* was close to five and a half times more likely than someone with no educational attainment to have perceived at least a moderate overall risk from swine flu.

Household income

Aggregate data (Table 5.2.9) reveal very similar proportions of people having a substantive overall risk perception (i.e. moderate, high or extreme perceived risk) across all income groups, ranging from 54.3% in the *$60-80k* group to 59.5% in the *$20-40k* group. A 5x2 Chi-square test examining for a difference between income groups for at least a moderate perceived risk from swine flu, did not reveal statistical significance ($\chi^2 = 0.28$, *p* = 0.99). For all income

Table 5.2.9 Perceived overall risk to self from swine flu if no protective measures taken: frequency (%) by estimated yearly household income (n = 309)

	< $20k (%)	$20-40k (%)	$40-60k (%)	$60-80k (%)	> $80k (%)
No risk at all	8.6	2.4	17.2	2.9	1.9
A small risk	35.5	38.1	27.6	42.9	42.7
A moderate risk	37.6	31.0	41.4	40.0	36.9
A high risk	10.8	11.9	10.3	5.7	17.5
An extreme risk	7.5	16.7	3.4	8.6	1.0
No risk at all or a small risk	44.1	40.5	44.8	45.7	44.7
Moderate, high or extreme risk	55.9	59.5	55.2	54.3	55.3

groups, "a small risk" and "a moderate risk" were the two most frequently reported risk perceptions. The group with the lowest proportion reporting "an extreme risk" (1%) was the *> $80k* group. Regression analysis (Table 5.2.7) was congruent with the group data findings. There was no statistical significance for either the overall variable *estimated annual household income* (*p* = 0.92), or for the dummy variables that coded for it in the model (i.e. *$20-40k*, *$40-60k*, *$60-80k* and *> $80k*), compared with the reference group, *< $20k*). Therefore, at the individual level, income was not a predictor of how likely it was for a person to have an overall risk perception of swine flu as 'moderate, high or extreme' compared to 'none, or only a little'.

Perceived likelihood of self contracting wine flu

Gender

Aggregate data show a higher proportion of women (54.0%) compared men (41.9%), reporting at least a moderate (i.e. moderate, high or extreme) perceived likelihood of contracting swine flu, if no protective measures were taken (Table 5.2.10). Chi-square test did find a statistically significant difference between the genders in this respect (χ^2 = 4.22, *p* = 0.04). In addition, the proportion of women perceiving an extreme risk (11.7%) was more than double than for men (5.4%). The perception of "not at all likely", "moderately likely" and "very likely" were fairly comparable, but a higher proportion of men (40.0%) saw their risk as "a little likely", compared with women (33.5%). The response with the highest frequency for both genders was "a little likely".

Table 5.2.10 Perceived likelihood of self contracting swine flu if no protective measures taken: frequency (%) by gender (n = 309)

	Male (%)	Female (%)
Not at all likely	15.4	11.7
A little likely	40.0	33.5
Moderate likely	24.6	29.1
Very likely	10.0	12.3
Extremely likely	5.4	11.7
Don't know	4.6	1.7
Not at all or only a little likely	58.1	46.0
Moderately, very or extremely likely	41.9	54.0

These aggregate data findings may lead to consideration of a *potential* hypothesis that female participants were more likely than male participants to perceive at least a moderate likelihood of contracting swine flu. However, an analytic approach using logistic regression analysis (Table 5.2.11) did find not a statistically significant gender difference ($p = 0.08$). Therefore, at an individual level a female participant was not more likely than a male participant to perceive a moderate, high or extreme likelihood of contracting swine flu.

Level of educational attainment

Aggregate data (Table 5.2.12) show fairly similar proportions of people having

an at least moderate perceived likelihood of contracting swine flu in the

Table 5.2.11 Perceived likelihood of self contracting swine flu if no protective measures taken, gender/SES as predictors: logistic regression (n = 309)

Predictor variable	B	df	*p* value	Exp(B)$
Gender	- 0.54	1	0.08	0.62
Highest level of education[#]		4	0.77	
Year 10 Certificate	- 0.13	1	0.79	0.81
Year 12 Certificate	0.70	1	0.98	0.98
TAFE certificate/diploma	- 0.06	1	0.86	0.87
University degree	- 0.34	1	0.55	0.63
Household income[#]		4	0.92	
$20-40k	0.24	1	0.57	1.20
$40-60k	- 0.12	1	0.81	0.84
$60-80k	0.16	1	0.74	1.08
> $80k	0.19	1	0.65	1.11

* statistical significance ($p < 0.05$)
$ adjusted for age, employment status, lives alone, children in household, self-rated health, diagnosis of schizophrenia
# coded for by dummy variables with "None" being the reference group for highest level of education, and "< $20k" for household income

various levels of educational attainment. The *Year 10 certificate* (44.4%) and

TAFE certificate / diploma (46.0%) groups were a little lower than *University*

degree (50%), *Year 12 certificate* (53.1%) and *None (50%).* In all educational

attainment groups except *None,* the most frequent response was "a little likely".

The highest frequency for those with no educational attainment was "not at all

likely", comprising a third of responses. A 5x2 Chi-square test examining for a

difference between educational groups for at least a moderate perceived

likelihood of contracting swine flu, did not reveal statistical significance (χ^2=

1.12, *p* = 0.90).

Table 5.2.12 Perceived likelihood of self contracting swine flu if no protective
measures taken: frequency (%) by highest educational attainment (n = 309)

	None (%)	Year 10 certificate (%)	Year 12 certificate (%)	TAFE certificate or diploma (%)	University degree (%)
Not at all likely	33.3	17.2	16.7	9.8	9.0
A little likely	8.3	34.5	28.8	43.1	41.0
Moderately likely	25.0	19.0	24.2	21.6	35.2
Very likely	8.3	12.1	13.6	13.7	9.0
Extremely likely	8.3	10.3	13.6	9.8	5.7
Don't know	16.7	6.9	3.0	2.0	0.0
Not at all or a little likely	50.0	55.6	46.9	54.0	50.0
Moderate, very or extremely likely	50.0	44.4	53.1	46.0	50.0

Mirroring these aggregate data findings, regression analysis (Table 5.2.11) did not find any statistically significance difference for *level of education* as predictor variable (*p = 0.82)* or for the 'dummy variables' that coded for it in the regression model. Therefore, at an individual level, a person with any of the various educational attainments was not more likely than an individual with no educational attainment, to have a perceived substantive likelihood of contracting swine flu.

Household income

Aggregate data (Table 5.2.13) reveal fairly similar proportions of people perceiving a substantive (i.e. moderate, high or extreme) likelihood of themselves contracting swine flu, in the *$20-40k* (53.7%), *$60-80k* (50%) and *> $80k* groups (52.4%). It was a little lower for the *< $20k* (44.8%) and *$40-60k* (42.9%) groups. For all income groups, "a little likely" and "moderate likely" were the most reported, and second most reported, respectively. A 5x2 Chi-square test examining for a difference between income groups for at least a moderate perceived likelihood of contracting swine flu, did not reveal statistical significance ($\chi^2 = 1.19$, $p = 0.76$).

Regression analysis (Table 5.2.11) showed no statistical significance for either the overall variable *estimated annual household income* ($p = 0.92$), or for the dummy variables that coded for it in the model (i.e. *$20-40k, $40-60k, $60-80k* and *> $80k*, compared with the reference group, *< $20k*). Therefore, at the

Table 5.2.13 Perceived likelihood of self contracting swine flu if no protective measures taken: frequency (%) by estimated yearly household income (n = 309)

	< $20k (%)	$20-40k (%)	40-60k (%)	$60-80k (%)	> $80k (%)
Not at all likely	17.2	9.5	10.3	8.6	12.6
A little likely	34.4	35.7	44.8	40.0	35.0
Moderately likely	24.7	23.8	20.7	25.7	34.0
Very likely	8.6	11.9	10.3	14.3	11.7
Extremely likely	8.6	16.7	10.3	8.6	6.8
Don't know	6.5	2.4	3.4	2.9	0.0
Not at all or a little likely	55.2	46.3	57.1	50.0	47.6
Moderate, very or extremely likely	44.8	53.7	42.9	50.0	52.4

individual level, income group was not a predictor of a person's perceived likelihood of himself or herself contracting swine flu in terms of it being 'moderate, high or extreme' compared to 'not at all likely or only a little likely'.

Perceived seriousness of contracting swine flu

Gender

As with the other risk perception dimensions discussed above, aggregate data show a higher proportion of women (59.0%) compared men (52.5%), reporting *at least* moderate (i.e. moderate, high or extreme) perceived seriousness from contracting the swine flu (Table 5.2.14). However, Chi-square test did not reveal a statistically significant difference between the genders in this respect ($\chi^2 = 1.23$, $p = 0.27$). The proportion of men and women reporting the various

levels of perceived seriousness, except for "very serious", were fairly comparable. However, the proportion of women who perceived contracting swine flu as "very serious" was higher than for men (21.2% compared with 13.8%). For both male and female participants, "a little serious" and "moderately serious" were the most reported (30.8% for men, 27.4% for women), and second most reported (28.5% for men, 26.3% for women) perceived seriousness levels, respectively.

Table 5.2.14 Perceived seriousness of self contracting swine flu if no protective measures taken: frequency (%) by gender (n = 309)

	Male (%)	Female (%)
Not at all serious	13.8	12.3
A little serious	30.8	27.4
Moderate serious	28.5	26.3
Very serious	13.8	21.2
Extremely serious	6.9	9.5
Don't know	6.2	3.4
Not at all or only a little serious	47.5	41.0
Moderately, very or extremely serious	52.5	59.0

Congruent with these only modest differences between male and female participants in the aggregate data findings, an analytic approach using

Table 5.2.15 Perceived substantive seriousness of self contracting swine flu, gender/SES as predictors: logistic regression (n = 309)

Predictor variable	B	df	*p* value	Exp(B)$^\$$
Gender	- 0.52	1	0.05	0.57
Highest level of education[#]		4	**0.04***	
None	0.88	1	0.94	1.06
Year 10 Certificate	0.88	1	**0.02***	**2.69**
Year 12 Certificate	0.28	1	**0.01***	**2.70**
TAFE certificate/diploma	- 0.15	1	0.30	1.50
Household income[#]		4	0.39	
< $20k	0.53	1	0.20	1.77
$20-40k	0.12	1	0.77	1.16
$40-60k	0.74	1	0.13	2.22
$60-80k	0.03	1	0.84	1.10

* statistical significance ($p < 0.05$)
$^\$$ adjusted for age, employment status, lives alone, children in household, self-rated health, diagnosis of schizophrenia
[#] coded for by dummy variables with "University degree" being the reference group for highest level of education, and "> $80k" for household income

regression analysis did not find any statistically significant gender differences

(Table 5.2.15). This means that it is not possible to conclude from the study

that, at an individual level, a man was less likely than a woman to perceive a moderate, high or extreme level of seriousness from contracting swine flu.

Level of educational attainment

Aggregate data (Table 5.2.16) show similar substantive (about two thirds) proportions of people perceiving catching swine flu as at least moderately serious, in the groups *Year 10 certificate* (67.3%) and *Year 12 Certificate* (66.7%). Proportions were also comparable (but lower than the above groups) in the *None* (54.5%) and *TAFE certificate/diploma* (55.1%) groups. The proportion of the *University degree* group perceiving contracting swine flu as at least moderately serious, was lower again (46.7%). A 5x2 Chi-square test examining for a difference between educational groups for at least a moderate perceived likelihood of contracting swine flu, did reveal statistical significance (χ^2 = 9.89, *p* = 0.04). In keeping with the previous two risk perception dimensions discussed earlier (*overall risk to self* and *likeliness of self* contracting swine flu), the *University degree* group had the lowest proportion of people reporting a perception of extreme seriousness in the event of contracting swine flu.

These aggregate data findings support consideration of a *potential* hypothesis that there is less likelihood of at least moderate perceived seriousness from contracting swine flu in people of with a university degree compared with those with lower educational attainment. Regression analysis revealed a statistically

Table 5.2.16 Perceived seriousness of self contracting swine flu if protective measures taken: frequency (%) by highest educational attainment (n = 309)

	None (%)	Year 10 certificate (%)	Year 12 certificate (%)	TAFE certificate or diploma (%)	University degree (%)
Not at all serious	16.7	6.9	4.5	11.8	20.5
A little serious	25.0	34.5	28.8	43.1	41.0
Moderately serious	8.3	24.1	36.4	31.4	32.0
Very serious	25.0	27.6	19.7	17.6	12.3
Extremely serious	16.7	8.6	7.6	11.8	6.6
Don't know	8.3	10.3	4.5	3.9	1.6
Not at all or a little serious	45.5	32.7	33.3	44.9	53.3
Moderate, very or extremely serious	54.5	67.3	66.7	55.1	46.7

significant difference (p = 0.04) for *level of education* as a predictor variable (with four degrees of freedom) as well as for "dummy variables" which coded for it in the regression model (Table 5.2.15). With *University degree* as the reference group, the exponential of coefficient B (i.e. the adjusted odds ratio) for both *Year 10 certificate* and *Year 12 certificate* was 2.7. Therefore, at an individual level, a participant with a *Year 10* or *Year 12 certificate* was more than two and a half times more likely to perceive contracting the swine flu as at least moderately serious compared with a person who had obtained a university degree.

Household income

Aggregate data (Table 5.2.17) show both similarities and variation in the proportions of people perceiving a substantive level of seriousness associated with contracting swine flu, among income groups. Although frequencies were similar for *$20-40k* (68.3%) and *$60-80k* (67.6%), there were differences between the remaining groups. Among those with estimated incomes under $20k, 58.6% perceived substantive seriousness, whereas the proportion was 50.0% and 47.0%, respectively, for the *$40-60k* and *> $80k* groups. However, a 5x2 Chi-square test examining for a difference between income groups for at least a moderate perceived seriousness of contracting swine flu, did not reveal statistical significance (χ^2 = 8.30, *p* = 0.08). For three groups *(< $20k, $20-40k* and *> $80k*) the two highest frequencies were "a little serious" and "moderately serious", but for the remaining two groups, "moderately serious" and "very serious" were the two responses with the highest frequencies.

Despite the Chi-square test results, these aggregate data might suggest a *potential* hypothesis that being in the income groups *$20-40k* or *$60-80k* was associated with a higher likelihood of perceiving a substantive level of seriousness from catching swine flu, compared with being in a household earning more than $80k. However, regression analysis (Table 5.2.15) showed no statistical significance for either the overall variable "household income" (*p* = 0.39), or for the dummy variables that coded for it in the model. In particular, there was no statistical significance for the exponential of

Table 5.2.17 Perceived seriousness of self contracting swine flu if no protective measures taken: frequency (%) by estimated yearly household income (n = 309)

	< $20k (%)	$20-40k (%)	40-60k (%)	$60-80k (%)	> $80k (%)
Not at all serious	8.6	14.3	20.7	8.6	16.5
A little serious	30.1	16.7	24.1	22.9	35.5
Moderately serious	25.8	31.0	17.2	37.1	28.2
Very serious	20.4	19.0	13.8	28.6	11.7
Extremely serious	8.6	16.7	13.8	0.0	5.8
Don't know	6.5	2.4	10.3	2.9	2.9
Not at all or a little serious	41.4	31.7	50.0	32.4	53.0
Moderate, very or extremely serious	58.6	68.3	50.0	67.6	47.0

coefficient B (i.e. adjusted odds ratio), for the *$20-40k* and the *$60-80k* groups, using > *$80k* as the reference group. Therefore, despite the findings at the group level, income group was not a predictor at the individual level of perceived seriousness of contracting swine flu in terms of it being 'moderate, high or extreme' compared to 'not at all likely, or only a little likely'.

Perceived vulnerability from swine flu pandemic

Gender

Aggregate data show fairly comparable proportions (about a third) of men (33.3%) and women (35.8%) reporting that they felt at least moderately vulnerable knowing that there was a global influenza pandemic (Table 5.2.18).

Chi-square test did not reveal a statistically significant difference between the genders for experiencing feelings of at least moderate vulnerability ($\chi^2 = 0.19$, $p = 0.66$). Proportions for each gender were fairly similar for all reported levels of perceived vulnerability, with the responses "a little vulnerable" and "not at all vulnerable" being the commonest responses (43.1% for men, 39.7% for women) and second commonest (20.0% for men, 23.5% for women) respectively, in both genders. Only a small minority of men (5.4%) and women (3.4%) felt extremely vulnerable.

The findings using an analytic approach (Table 5.2.19) mirrored those of the ecological approach, with regression analysis showing no statistically

Table 5.2.18 Perceived vulnerability from swine flu: frequency (%) by gender (n = 309)

	Male (%)	Female (%)
Not at all vulnerable	20.0	23.5
A little vulnerable	43.1	39.7
Moderate vulnerable	15.4	20.1
Very vulnerable	10.8	11.7
Extremely vulnerable	5.4	3.4
Don't know	5.4	1.7
Not at all or only a little vulnerable	66.7	64.2
Moderately, very or extremely vulnerable	33.3	35.8

Table 5.2.19 Perceived substantive vulnerability from swine flu, gender/SES as predictors: logistic regression (n = 309)

	B	df	*p* value	Exp(B)$^\$$
Gender	- 0.22	1	0.32	0.75
Highest level of education[#]		4	0.54	
None	0.49	1	0.89	0.88
Year 10 certificate	- 0.18	1	0.24	1.61
Year 12 certificate	0.41	1	0.66	0.84
TAFE certificate/diploma	- 0.15	1	0.31	1.51
Household income[#]		4	0.16	
< $20k	0.22	1	0.51	1.35
$20-40k	0.87	1	0.06	2.58
$40-60k	- 0.19	1	0.88	0.92
$60-80k	- 0.42	1	0.51	0.74

* statistical significance ($p < 0.05$)
$^\$$ adjusted for age, employment status, lives alone, children in household, self-rated health, diagnosis of schizophrenia
coded for by dummy variables with "University degree" being the reference group for highest level of education, and "> $80k" for household income

significant differences between the genders in terms of having at least moderate feelings of vulnerability ($p = 0.32$). Therefore, there was no effect of gender at the level of the individual on the likelihood of having feelings of substantive vulnerability as a result of the global influenza pandemic.

Level of educational attainment

Aggregate data (Table 5.2.20) show the same proportion (44.4%) of people having at least moderate feelings of vulnerability from pandemic swine flu in those with no educational attainment and *Year 10 certificate.* The educational attainment group with the next highest frequency for at least moderate perceived vulnerability was *TAFE Certificate/Diploma* (40.0%), followed by *Year 12 Certificate* (32.3%) and *University degree* (28.9%). Easily the highest proportion of responses in each educational attainment group was "a little vulnerable", being 25% in those with no educational attainment, and ranging between 39.2% and 43.9% in the remaining four educational attainment categories.

These group findings may support consideration of a potential hypothesis that people with no educational attainment or only Year 10 certificate were more likely to feel at least moderately vulnerable knowing about the prevailing influenza pandemic compared with people with a university degree. However, regression analysis did not find any statistically significance ($p = 0.54$) difference for *level of education* as an 'overall variable' with four degrees of freedom or for any of the 'dummy variables' which coded in the regression model. Therefore, at an individual level, educational attainment was not a predictor for having substantive feelings of vulnerability due to the prevailing swine flu pandemic.

Table 5.2.20 Perceived vulnerability from swine flu: frequency (%) by highest educational attainment (n = 309)

	None (%)	Year 10 certificate (%)	Year 12 certificate (%)	TAFE certificate or diploma (%)	University degree (%)
Not at all vulnerable	16.7	8.6	22.7	19.6	29.5
A little vulnerable	25.0	43.1	43.9	39.2	41.0
Moderately vulnerable	16.7	20.7	16.7	21.6	16.4
Very vulnerable	16.7	15.5	9.1	11.8	9.8
Extremely vulnerable	0.0	5.2	6.1	5.9	2.5
Don't know	25.0	6.9	1.5	2.0	0.8
Not at all or a little vulnerable	55.6	55.6	67.7	60.0	71.1
Moderate, very or extremely vulnerable	44.4	44.4	32.3	40.0	28.9

Household income

Aggregate data (Table 5.2.21) show considerable variation in the proportions of people experiencing substantive levels of vulnerability from knowing about the prevailing swine flu, among different income groups. These proportions varied from a little over a quarter (26.5%) in the *> $80k* group, to approaching a half (46.4%), in the *$40-60k* group. The response with the highest frequency in all income groups was "a little vulnerable", ranging from 27.6% in the

Table 5.2.21 Perceived vulnerability from swine flu: frequency (%) by estimated yearly household income (n = 309)

	< $20k (%)	$20-40k (%)	40-60k (%)	$60-80k (%)	> $80k (%)
Not at all vulnerable	17.2	11.9	20.7	8.6	33.0
A little vulnerable	38.7	45.2	27.6	57.1	39.8
Moderately vulnerable	19.4	19.0	24.1	11.4	16.5
Very vulnerable	10.8	19.0	13.8	17.1	6.8
Extremely vulnerable	5.4	4.8	6.9	2.9	2.9
Don't know	8.6	0.0	3.4	0.0	1.0
Not at all or a little vulnerable	61.2	57.1	53.6	68.6	73.5
Moderate, very or extremely vulnerable	38.8	42.9	46.4	31.4	26.5

$40-60k group to $45.2% in the *$20-40k* group. Only a relatively low proportion of participants in each income group reported experiencing extreme feelings of vulnerability, ranging from 2.9% in the *> $80k* group to 6.9% in the *$40-60k* group.

These aggregate data might suggest consideration of a possible hypothesis that being in the income group *$40-60k* was associated with a higher likelihood of feeling at least moderately vulnerable from swine flu compared with living in a household earning more than $80k. However, regression analysis did not show statistical significance ($p = 0.16$) for the contribution of the overall

variable *household income* with four degrees of freedom, or for any of the dummy variables representing its contribution to the model.

5.2.5 Discussion

Risk perception

As discussed in chapter two, risk perception continues to be an area of active research. Although there is no unified understanding of how people assess their own risk, it is generally agreed that risk perception of an illness can be conceptualized as comprising two core dimensions - perceived *likelihood* of developing the illness and perceived *seriousness* of the illness. Despite the socio-demographic differences between people with schizophrenia and those in the broader population, the present study found no statistically significant differences between these two groups in perceived overall risk, or in either of these core dimensions of risk perception, with respect to swine flu. In order to speculate why this finding occurred it is helpful to examine factors which, as the literature has established, have the capacity to influence the perception of illness risk. As described in chapter two, these include *perceived control* over the illness (Moore & Rosenthal 1996), knowledge of the *illness experience* (Moore & Rosenthal 1996; Millstein & Halpern-Felsher 2002), *factual knowledge* of the illness (De Noouer et al. 2001), *affective response* (Finucane et al. 2000), and *trust* in information sources (Slovic 2000; Rubin et al. 2009).

There was a strong similarity on a group level in the proportion of people perceiving they had control over contracting swine flu. In the SCZ group 63.6%

of participants believed they could avoid contracting the infection, with 63.4% of people in the GP group holding a similar view. On an analytic level using regression analysis there was no difference between the groups in perceived control over contracting the illness. Similarly, there were striking similarities in knowledge of the *illness experience* between the SZC group (39%) and the GP group (40%). Again, at an individual level, there were no statistically significant differences on regression analysis. There were group differences in predicted affective response (SCZ group more likely to predict feeling both afraid and depressed if swine flu were contracted compared with GP group) but no significant differences on regression analysis. There were differences in factual knowledge of influenza at both a group and individual level and in trust in information sources with respect to doctor. Therefore, on balance there were more similarities than differences in the factors that influenza risk perception, which may in explain in part the similar swine influenza risk perception. Finally, the fact that H1N109 was found and reported to be a hypovirulent strain, with a lower case fatality rate than seasonal flu, may have also had a bearing on similarities in risk perception.

Comparison with other studies

With respect to perceived likelihood of contracting swine flu, the results are similar to other surveys of H1N109. For instance, in a study of community responses in the early phases of swine flu outbreak in Hong Kong, only about 8% of respondents reported believing the risk of contracting the virus was high or very high (Lau et al. 2009). Similarly, a cross-sectional survey of adults

visiting shopping and pedestrian malls in Sydney, conducted in September and October 2009, found a relatively low proportion of participants (15.8%) reporting a high, or very high, perceived risk from swine flu (Seale et al. 2010). Regarding perceived seriousness, a Dutch online survey in November 2009, found lower levels than both of the groups in this thesis study, with 38% of respondents viewing H1N109 as serious (Bults et al. 2010). The later time frame of the study may have contributed to this difference.

Factual knowledge

It was not surprising to find that participants in the SCZ group had less knowledge of influenza than the GP group, even after *highest educational attainment* was controlled for. Factors such as cognitive deficits and the negative syndrome of schizophrenia are likely to impact on the ongoing acquisition of knowledge, especially involving recently released information about swine flu. As discussed earlier in the information sources results section, it appears that doctors and the Internet are less likely to be used to access health information in people with schizophrenia, compared with the general population. An important caveat in comparing the extent of knowledge about influenza in SCZ and GP groups is that, as discussed earlier, the level of educational attainment among adults in the ACT is disproportionately high compared with other stated and the Northern Territory. In addition, a deficiency in knowledge of H1N109 has not been restricted to people with a mental illness. In a telephone survey of a general adult general population conducted in August and September 2009 (Eastwood et al. 2010), knowledge of swine flu

was tested with four 'True of False' questions examining transmission, symptoms and infection control measures. Only 14.5% of participants answered all questions correctly. However, a direct comparison between the results of the Eastwood et al. study and the thesis study is limited by differences in the methods used to assess factual knowledge about influenza.

Predictors of risk perception

For both groups in the present study, *perceived likelihood* of contracting swine flu was a strong positive predictor of perceived overall risk to oneself from swine flu during the pandemic, but about three times more so for the SCZ group. *Perceived seriousness* of contracting swine flu was a positive predictor for perceived overall risk from swine flu for the SCZ group but for not the GP group. This may relate in part to participants with schizophrenia possibly not accessing information sources as readily and comprehensively as people without this illness, and therefore, not having acquired the knowledge that the H1N109 virus was not a hypervirulent strain. However, it may also reflect that people with schizophrenia may be correct in their perception and in fact are at greater risk because they are more likely to have serious complications from influenza, as a vulnerable group (as described in chapter 1). Unsurprisingly, poor self-rated health was a strong positive predictor of perceived risk from H1N109 for people with schizophrenia. Although female gender (De Zwart et al. 2007; Ibuka et al. 2010; Akan et. al 2010) and older age group (De Zwart et al. 2010) have been found to be associated with greater perception of personal risk associated with pandemic influenza (including H1N109), the thesis study

did not reveal any of the socio-demographic variables as statistically significant predictors in the within-group analyses. However, in the broader analysis at a whole sample level, *level of educational attainment* was a predictor for risk perception. Holding a TAFE certificate or diploma, compared to no educational attainment, made it more likely to perceive a substantive overall risk from swine flu but holding either a Year 10 or Year 12 certificate made it more likely to perceive swine flu as serious compared with having a university degree.

Neither *factual* knowledge of the disease, nor knowledge of the disease *experience,* predicted perceived risk to self from swine flu, in either group. Furthermore, unlike findings in a US online survey in April / May 2009 (Ibuka et al. 2010), which revealed a reduction in perceived risk to self over time during the H1N109 pandemic, the thesis study did not show changes in perceived risk (at a group level rather than at an individual level, as participants were surveyed at only one time point) over the time of the study. Affective predictors of perceived risk to self from swine flu are discussed below.

Role of affect - "risk as feelings"

Slovic and his research colleagues have emphasized the importance of affect in the perception of risk, in addition to purely cognitive processes. For instance, as described in chapter one, they found that a "feeling of dread" towards a potential hazard (e.g. nuclear power or terrorism) correlated with increased perception of risk from that hazard. Gigerenzer (2007) has similarly described a role for "gut feelings" in making decisions. The present study revealed a

5-fold increased likelihood of a substantive perceived risk to self from swine flu in those people with schizophrenia who predicted that they would "feel afraid" in the event of contracting swine flu in the future. However, an anticipated depressed mood if swine flu were contracted in the future was, in the SCZ group, associated with a 3½-fold reduced likelihood of perceiving a substantive risk from the pandemic. Anticipated affective response (of either fear or depressed mood) was not a statistically significant predictor of perceived personal risk from H1N109, for the GP group. These findings, suggestive of a role for affect in the perception of risk for people in the SCZ group but not for those in the GP group, are somewhat surprising given the emotional blunting that is often a part of the negative syndrome experienced by people schizophrenia.

As discussed in chapter two, risk appears to be perceived in two fundamental modes. The first, "risk as feelings", provides a rapid, affective, intuitive response to a threat. The second mode is a slower, deliberate, logical, cognitive appraisal of the threat. As the emotional reaction to a threat usually occurs quickly and is likely to influence the cognitive aspects of risk perception, the influence may be bi-directional. Finucane et al. (2000) demonstrated that by presenting cognitively favourable or unfavourable information about hazards" such as nuclear power, it was possible to manipulate the affective response of volunteers, which in turn, influenced beliefs about benefits and risks.

In the present study, a higher K10 total score, higher K10 anxiety subscale score, and K10 score ≥ 20 (versus a score < 20) were all associated with a reduced likelihood of perceiving a substantive risk to self from swine flu for the SCZ group, but were not predictors of perceived personal risk from swine flu for the GP group. K10 total scores indicate concurrent levels of psychological distress of participants, unlike the affective forecasts discussed above, which relate to a *prediction* of feeling "afraid" or "depressed" in the *future* if swine flu were contracted. It seems possible that these findings for people with schizophrenia may relate to the concept of a *finite pool of worry*, which originated in the climate literature two decades ago (Linville & Fischer 1991). This term describes the phenomenon that a person's increase in worry about one hazard may lead to a reduction in worry about other hazards (such as swine influenza). It could be speculated that people with schizophrenia often already have many significant challenges to worry about in their day to day lives, and, therefore, may have a higher threshold with respect to worry about a new threat, such as pandemic influenza.

5.2.6 Limitations

There are several limitations specifically related to this aspect of the study. Challenges exist for comparison of risk perceptions in the thesis study to the findings in research about a hypothetical future "generic" pandemic influenza, given that the present study was conducted *during* a global pandemic that received considerable media attention at the time. In addition, comparison with research on avian influenza, which has received a very public focus, is

problematic in light of the strikingly different case fatality rates between H5N1 and H1N109 strains. In the thesis study there was no apparent temporal relationship with risk perception using aggregate data. However, for a *given* individual, risk perception may have varied over time. A longitudinal study surveying a cohort of participants at several time points during the pandemic would be required to detect this. Finally, there are limitations in assessing knowledge of influenza by two questions using a dichotomous scoring system.

5.2.7 Practical implications

For people with schizophrenia, this study suggests there are poor levels of factual knowledge about influenza in terms of symptoms that characterize it, and its duration. Therefore, it is likely to be important during the early phases of an influenza outbreak for health authorities to specifically target and assist this population with educational processes, especially with regard to what symptoms to be vigilant for and where to go and what to do if these symptoms occur. When reviewing and modifying pandemic influenza response plan strategies, as well as protocols and action plans in public health care settings, it will be useful to know that for people with schizophrenia, higher perceived *likelihood* of contracting the influenza and higher perceived *seriousness* are strong predictors of perceived overall risk to self from the influenza outbreak, and could reflect real vulnerabilities. Given that *perceived risk* of a health threat can influence *willingness* to undertake protective measures against that health threat, it important that people with schizophrenia receive accurate information on (1) vulnerability factors which can increase the *seriousness* of contracting

influenza e.g. existing heart or lung disease, diabetes mellitus, pregnancy, and factors which increase the *likelihood* of contracting it (such as smoking), (2) ways in which the influenza is spread from person to person, and effective protective measures to minimize one's risk of contracting influenza, and (3) potential complications of influenza, which have a bearing on potential *seriousness* for a person who has contracted it.

5.2.8 Conclusion

There are strong similarities in the way people with schizophrenia attending public mental health settings, and people without schizophrenia attending general practice settings, perceived the 2009 pandemic influenza. No statistically significant differences existed between the two groups in: (1) reported perception of overall risk to self from swine flu (with a little over 50% in both groups perceiving substantive risk); (2) perceived likelihood of themselves contracting the swine flu in Australia; (3) perceived seriousness for themselves in they contracted swine flu; (4) perceived control over contracting swine flu i.e. the ability to avoid contracting it; (5) feelings of vulnerability about the swine flu; and (6) predicted affective response if they were to contract swine flu at some time in the future during the concurrent pandemic. However, there was a statistically significant difference between the two groups for factual knowledge of influenza. People without schizophrenia demonstrated a better knowledge of symptoms characterizing the disease and its duration. There were both similarities and differences between the two groups of participants in terms of predictors of perceived overall risk to self from swine flu

during the pandemic. A predictor for both groups was perceived likelihood of oneself contracting swine flu. For people with schizophrenia statistically significant additional positive predictors of a substantive perceived risk to self from swine flu included: (1) perceived seriousness of oneself contracting swine flu; (2) poorer general self-rated health; and (3) lower K10 scores (total score, anxiety subscale score, and score < 20 versus ≥ 20). For the people without schizophrenia the only additional predictor of perceived overall risk to self from the swine flu pandemic was perceived likelihood of death as a result of contracting swine flu.

5.3 Willingness to adopt protective measure against pandemic influenza

5.3.1 Introduction

As discussed in chapter two, a core component of an effective response in combating a pandemic influenza is preventative health actions, both vaccination and infection control measures. Epidemiological computer analyses using stochastic simulation models have suggested that uptake of protective measures by only a modest number people can have a significant impact on the trajectory of a pandemic influenza (Halloran et al. 2008; Ibuka et al. 2010). The dynamics of viral transmission in a pandemic influenza are related to the average number of secondary cases produced by each primary case at the beginning of the pandemic (R_0), and the average period of time between infection of an index case and infection of a secondary case (T_g). Experts in the field indicate that it is reasonable to assume an $R_0 < 2$ and a T_g as short as three days, in a newly emergent pandemic influenza (Halloran et al. 2008). Even with an influenza case ascertainment rate as low as 60%, and compliance with protective measures only 30%, simulation analysis still predicted an 85% reduction in influenza attack rates (i.e. number of people infected by the virus divided by the number exposed to the virus). Although a pandemic influenza can be explosive in nature, there is still the potential to contain it by employment of simple infection control methods, because reducing viral transmission by a half can result in a reduction of R_0 to < 1. Therefore, there is value in acquiring knowledge of individuals' willingness to engage in protective behaviours during a pandemic and factors that influence

this willingness. Protective behaviour is linked to a person's risk perceptions of the health threat as well as their evaluation of the potential benefits and liabilities associated with a given preventive action (Brewer et al. 2007). Also important is self-efficacy, which refers to the individual's belief that they are able to carry out the action. Self-efficacy has been shown to significantly facilitate adaptive health intentions and behaviours (Floyd et al. 2000). It is included as a component of health behaviour models such as the Protection Motivation Theory (Rogers 1975) and Health Belief Model (Rosenstock 1974). Previous studies have shown that willingness to adopt precautionary measures during a serious outbreak of respiratory infection, including SARS and H1N109, is associated with:

(1) Perceived severity of illness (Chor et al. 2009; Rubin et al. 2009; Lau et al. 2010)

(2) Perceived likelihood of oneself contracting the infection (Leung et al. 2003; Chor et al 2009; Rubin et al. 2009; Lau et al. 2010; Setbon & Raude 2010)

(3) Duration of outbreak (willingness decreased over time) (Rubin et al. 2009)

(4) Perceived effectiveness and risks associated with the protective action (Lau et al. 2003; Tang et al. 2004)

(5) Anxiety about the outbreak (Goodwin et al. 2009; Jones & Salathe 2009; Rubin et al. 2009; Lau et al. 2010)

(6) Previous influenza vaccination (Setbon & Raude 2010; Seale et al. 2010)

Therefore, these factors can potentially influence the *behavioural uptake* of measures that provide significant protection to the individual and others in the

community during a pandemic influenza. Results, limitations and practical implications of the thesis study related to willingness to adopt protective measures, are presented and discussed.

5.3.2 Vaccination

In the SCZ group, 74.3% of participants were at least moderately willing to receive a vaccination compared with 80.1% in the GP group (Table 5.3.1). Approximately 52% of people in the SCZ group were *very or extremely* willing to be vaccinated compared with 63% in the GP group. Independent samples t-test (Table 5.3.4) and Mann-Whitney U Test (Mann Whitney U = 7818.5, p = 0.32) did not show a statistically significant difference at a group level. However, between-group regression analysis (Table 5.3.1) revealed that people with schizophrenia were less likely to be willing to receive vaccination than participants in the GP group. They also perceived vaccination as riskier for an adverse reaction and had more concern about "catching the flu" from vaccination. There were no statistically significant differences for self-efficacy. Within-group analysis (Tables 5.3.2, 5.3.3) revealed that, for participants in the SCZ group, positive predictors of willingness to receive a flu vaccination included perceived self-efficacy, perceived likelihood of contracting H1N109 and an anticipation of experiencing fear in the event of contracting H1N109. In the GP group, positive predictors of willingness to be vaccinated included perceived effectiveness of vaccination, and self-efficacy. Those in the GP group who perceived a substantive risk of adverse reaction were less likely

Table 5.3.1 Comparison between SCZ and GP groups for willingness to adopt protective measures against pandemic influenza

Precautionary measure$	SCZ (%) (n=71)	GP (%) (n=238)	AOR (95% CI)	p
Vaccination				
Willing to receive	74.3	80.1	**0.41 (0.19-0.88)**	**0.02***
Perceived as effective	86.6	75.3	1.63 (0.69-3.86)	0.27
Perceived as risky for adverse reaction	38.7	27.5	**2.17 (1.03-4.56)**	**0.04***
Concern about "catching" flu from vaccination	71.8	50.2	**2.19 (1.48-3.25)**	**0.02***
Self-efficacy	85.5	76.5	0.72 (0.44-1.17)	0.43
Isolation				
Willing to be isolated	73.2	86.1	**0.41 (0.25-0.65)**	**0.03***
Perceived as effective	69.7	80.9	0.52 (0.33-0.81)	0.09
Self-efficacy	61.8	72.6	**0.44 (0.29-0.66)**	**0.02***
Face mask				
Willing to wear	54.9	61.6	0.44 (0.49-1.17)	0.40
Perceived as effective	45.5	57.7	0.52 (0.27-1.01)	0.05
Self-efficacy	63.2	66.0	0.90 (0.45-1.79)	0.77
Hand washing				
Willing to wash hands more frequently	88.6	93.2	0.78 (0.25-2.41)	0.58
Perceived as effective	77.3	85.6	0.62 (0.27-1.41)	0.17

$ At least a moderate of that variable (e.g. *willingness to receive vaccination* denotes reporting being moderately, very or extremely willing) except for *concern about catching flu from a vaccination* which denotes any degree of concern at all i.e. at little, moderate, a lot or extreme amount; * statistical significance ($p < 0.05$); AOR, adjusted odds ratio (adjusted for age, gender, socio-economic status, living alone, children in the household, non-English language spoken at home, week of participation, self-rated health, previous influenza experience and K10 total score); SCZ, schizophrenia; GP, general practice

to be willing to have a vaccination. Although greater age was a statistically significant positive predictor in the GP group ($p < 0.05$) it was not clinically relevant, with an adjusted odds ratio almost equal to one (AOR = 0.96).

Table 5.3.2 Predictors of willingness to adopt protective measures: within-group multiple logistic regression (Exp(B) with *p* values)

Predictor	Vaccination		Isolation		Face mask		Increased hand washing	
	SCZ	GP	SCZ	GP	SCZ	GP	SCZ	GP
Age	1.01 (0.80)	**0.96 (0.01*)**	1.16 (0.05)	**1.05 (0.02*)**	1.10 (0.05)	1.02 (0.27)	1.03 (0.57)	0.98 (0.57)
Gender (male)	1.76 (0.58)	1.09 (0.87)	4.54 (0.19)	0.90 (0.84)	1.75 (0.48)	0.81 (0.61)	2.49 (0.48)	0.24 (0.05)
Employed	1.08 (0.95)	1.12 (0.84)	0.68 (0.73)	0.42 (0.16)	1.14 (0.88)	1.29 (0.59)	0.34 (0.38)	1.38 (0.65)
Highest level of education	-	-	-	**40.00# (0.03*)**	**0.02$ (0.02*)** **0.02# (0.03*)**	-	-	-
Self-rated general health	1.38 (0.64)	1.04 (0.89)	0.36 (0.22)	0.75 (0.33)	1.41 (0.51)	**1.75 (0.02*)**	0.79 (0.76)	**0.33 (0.02*)**
Perceived effectiveness	1.67 (0.29)	**3.68 (< 0.01*)**	**5.23 (0.01*)**	1.25 (0.29)	1.27 (0.58)	**2.48 (< 0.01*)**	2.98 (0.09)	**3.68 (< 0.01*)**
Perceived risk of adverse reaction	0.55 (0.11)	**0.58 (0.01*)**	nd	nd	nd	nd	nd	nd
Perceived self-efficacy	**3.44 (0.04*)**	**1.72 (< 0.01*)**	**4.89 (0.01*)**	**2.18* (< 0.01*)**	**2.43 (0.02*)**	**3.01 (< 0.01*)**	nd	nd
Perceived own likelihood of contracting H1N109	**3.48 (0.04*)**	0.91 (0.69)	1.53 (0.53)	0.83 (0.41)	0.59 (0.22)	1.41 (0.22)	0.31 (0.12)	0.92 (0.76)
Perceived seriousness of contracting H1N109	2.16 (0.16)	1.13 (0.64)	0.83 (0.77)	1.31 (0.28)	0.62 (0.32)	1.31 (0.22)	1.65 (0.48)	0.99 (0.98)
Feeling vulnerable to H1N109	1.07 (0.88)	1.35 (0.29)	0.53 (0.25)	0.83 (0.47)	0.93 (0.85)	1.11 (0.65)	3.34 (0.16)	0.61 (0.20)
Perceived overall risk from H1N109	0.76 (0.58)	1.05 (0.88)	4.82 (0.08)	1.35 (0.33)	**5.61 (0.01*)**	1.27 (0.39)	1.72 (0.52)	**3.65 (0.01*)**

* statistical significance ($p < 0.05$); Exp(B), exponential of regression coefficient B; nd, no data
# **"*University degree*"** compared with *no educational attainment* (using dummy variables to represent highest educational attainment, reference group = "*None*")
$ "*Year 10 certificate*" compared with *no educational attainment* (using dummy variables to represent highest educational attainment, reference group = "*None*")
  SCZ, schizophrenia; GP, general practice

Table 5.3.3 Anticipated affective response if infected with H1N109, as predictor of willingness to comply with protective measures: within-group logistic regression (adjusted odds ratios with *p* values)

	Vaccination		Isolation		Face mask		Increased hand washing	
	SCZ	**GP**	**SCZ**	**GP**	**SCZ**	**GP**	**SCZ**	**GP**
"Make you feel afraid"	**2.33 (0.04*)**	1.37 (0.08)	1.52 (0.20)	1.26 (0.28)	**3.10 (0.01*)**	**1.50 (< 0.01*)**	**15.20 (0.02*)**	1.11 (0.67)
"Make you feel depressed"	1.33 (0.29)	1.50 (0.05)	0.92 (0.74)	1.12 (0.58)	**2.49 (0.01*)**	1.29 (0.08)	1.62 (0.37)	1.06 (0.82)

* statistical significance (*p* < 0.05); odds ratios adjusted for age, gender, employment status, highest level of education, general self-rated health and K10 total score

SCZ, schizophrenia; GP, general practice

5.3.3 Social isolation

In the SCZ group, 73.2 % of participants were at least moderately willing to isolate themselves from others, if directed to by government authorities, compared with 86.1% in the GP group (Table 5.3.1). An independent samples t-test (Table 5.3.4) (p = 0.05) and Mann-Whitney U Test (Mann Whitney U = 7158.5, p = 0.05) narrowly missed showing a statistically significant difference at a group level. Only 46.5% of people in the SCZ group were *very or extremely* willing to isolate themselves compared with 61.3% in the GP group. Between-group regression analysis (Table 5.3.1) revealed that participants with schizophrenia were less likely to be willing to isolate themselves during a pandemic influenza and less likely to have self-efficacy to undertake this action. Within-group analysis showed that in the SCZ group, positive predictors for willingness to isolate oneself included perceived effectiveness of isolation and self-efficacy. In the GP group, self-efficacy and higher education (university degree versus no educational attainment) were positive predictors. Greater age, although a statistically significant positive predictor ($p < 0.05$), had no clinical relevance, with an adjusted odds ratio almost equal to one (AOR = 1.05).

5.3.4 Face mask

There were no statistically significant differences between the SCZ and GP groups, in terms of their willingness to wear a face mask, either at a group level (Mann-Whitney U = 8278.5, p = 0.83; see Table 5.3.4 for t-test), or on regression analysis (Table 5.3.1). Similarly there were no differences between

the groups in perception of its effectiveness or in self-efficacy. Of all the precautionary measures examined in both groups, wearing a face mask appeared to be the least likely to be adhered to and the most likely to be viewed as ineffective or minimally effective. In the SCZ group, 39% of volunteers were *very or extremely* willing to wear a mask compared to 34% in the GP group. Within-group analysis revealed that in the SCZ group, positive predictors of willingness to wear a face mask included self-efficacy, perceived

Table 5.3.4 Between-group differences in willingness to adopt protective measures during a pandemic influenza using Likert scale means (independent-samples t-test and Levene's test for homogeneity of variance)

| | Mean | | t | *p* | Eta squared | Levene's test | |
						F	*p*
	SCZ (n=71)	GP (n=238)					
Vaccination	3.73	3.55	0.10	0.32	< 0.01	1.13	0.28
Isolation	3.65	3.32	2.15	**0.05**	0.01	4.27	0.04*
Face mask	2.90	2.96	-0.35	0.75	< 0.01	8.11	0.01
Hand washing	4.12	3.86	1.95	0.05	0.01	2.68	0.10

* statistical significance ($p < 0.05$); Cohen's criteria for eta squared: 0.01 = small effect, 0.06 = medium effect, 0.14 = large effect; SCZ, schizophrenia; GP, general practice

overall risk from swine flu, and an anticipated feeling of being afraid or depressed if swine flu were contracted. A higher level of educational attainment was a negative predictor. Having either a Year 10 certificate or university degree was associated with being 50-fold less likely to be willing to wear a face mask compared with those with no educational attainment. In the GP group, self-efficacy, perceived effectiveness, affective forecast of fear in the event of contracting swine flu, and higher self-rated general health, were positive predictors of willingness to wear a face mask.

5.3.5 Hand washing

There were no statistically significant differences between the SCZ and GP groups, in terms of being at least moderately willing to increase hand washing, either at a group level (Mann-Whitney U = 7148.0, p = 0.06; see Table 5.3.4 for t-test), or on regression analysis (Table 5.3.1). A high proportion (approximately 90%) of participants in both groups was willing to engage in this precautionary measure. In addition, over three quarters of people in each group evaluated increased hand washing as an effective preventative action. Affective forecast of fear related to contracting H1N109 was a particularly strong predictor of willingness to increase hand washing in the SCZ group. Perceived effectiveness, perceived overall risk from H1N109 and poorer self-rated general health were positive predictors of increased hand washing willingness in the GP group.

5.3.6 Temporal factors

Exploratory analysis employing logistic regression revealed no statistically significant temporal relationship between the week of participation in the study and willingness to adopt any of the protective measures. This analysis was performed to explore whether there was a reduction in willingness (at a group level) to adopt protective actions as time elapsed and more information became available to the public on the low fatality rate of the H1N109 virus, as was found in a large online US study (Ibuka et al. 2010).

5.3.7 Affective factors as predictors

There were clear differences between the SCZ and GP groups regarding their anticipated affective response (in the event of contracting swine flu) as a predictor of willingness to undertake protective measures (Table 5.3.3). For participants with schizophrenia affective forecast of fear was a robust and statistically significant predictor for all protective measures except isolating oneself. It was a particularly powerful predictor for willingness to increase hand washing, with an adjusted odds ratio of 15.20. In the GP group an affective forecast of fear was only a weak predictor (AOR = 1.50) for wearing a face mask. A prediction of feeling depressed in the event of becoming infected with H1N109 was a predictor of willingness only in the SCZ group, where it was associated with a increased likelihood of being willing to wear a face mask (AOR = 2.49). There was no association between K10 total score, representing the level of current psychological distress, and willingness to adopt any of the precautionary measures for either group. Correlations with willingness were

also sought using subscales of the K10 Psychological Distress Scale. Neither K10 anxiety nor the depression subscale score was a statistically significant predictor of willingness to adopt any of the protective measures for either the SCZ or GP group. In addition, the dichotomous variable K10 score ≥ 20 (versus a score below 20) was not a statistically significant predictor of any protective measure in either group (Table 5.3.5).

5.3.8 Discussion

Overview

The results suggest that people with schizophrenia as well as the general public, had substantive levels of willingness to take protective actions against the pandemic influenza in Australia in 2009, if advised to by government authorities. More than half of the participants in each group reported being willing to receive a vaccination, as well as to adopt each of the non-pharmacological interventions. In both groups, increased hand washing was the most accepted measure and wearing a face mask the least accepted. However, when potential confounders were adjusted for, people with schizophrenia were found to be less likely to be willing to receive a vaccination or to isolate themselves, potentially placing them at a disadvantage, especially given their vulnerability to influenza. In terms of socio-demographic characteristics, *level of education*, was a very strong predictor of willingness for both groups of participants, but exerted its effects in different directions, being a negative predictor for people with schizophrenia for wearing a face mask but a positive predictor for the general public for isolating themselves.

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Table 5.3.5 K10 scores as predictors of willingness to adopt protective measures: within-group logistic regression (adjusted odds ratios with p values)

	Vaccination		Isolation		Face mask		Increased hand washing	
	SCZ	GP	SCZ	GP	SCZ	GP	SCZ	GP
K10 total score	0.97 (0.54)	0.98 (0.48)	1.07 (0.22)	0.97 (0.43)	1.02 (0.07)	1.00 (0.86)	1.18 (0.07)	1.02 (0.67)
K10 anxiety subscale	1.04 (0.69)	0.90 (0.10)	1.65 (0.50)	0.94 (0.42)	1.02 (0.86)	1.31 (0.12)	1.31 (0.12)	1.02 (0.86)
K10 depression subscale	0.91 (0.24)	1.00 (0.99)	1.12 (0.22)	0.97 (0.51)	1.32 (0.06)	1.04 (0.57)	1.32 (0.06)	1.04 (0.57)
K10 total score ≥ 20	0.65 (0.55)	0.70 (0.34)	1.65 (0.50)	0.69 (0.42)	1.81 (0.37)	0.83 (0.76)	14.22 (0.05)	0.83 (0.76)

K10, 10-item Kessler Psychological Distress Scale; odds ratios adjusted for age, gender, employment status, highest level of education and self-rated health; SCZ, schizophrenia; GP, general practice

Willingness: comparison with other studies

The cross sectional telephone survey of the general population of NSW (Barr et al. 2008), which did not include hand washing, found the following proportion of participants at least moderately willing to adopt a given precautionary measure: vaccination 89%, isolation 85%, and face mask 79%. These levels were higher than both groups in the present study, except for isolation in the GP group, which was marginally higher than in the NSW study. The relatively greater willingness to adopt protective behaviours in the NSW study may relate to a hypothetical future pandemic influenza being perceived as more serious, with speculation that it might be a bird flu pandemic with a high case fatality rate. However, the rank order of willingness to adopt different protective actions (excluding hand washing) was the same: vaccination the highest, followed by social isolation and wearing a face mask. A Dutch online survey of the H1N109 pandemic conducted in mid-November 2009 (Bults et al. 2010) found that 58% of respondents indicated a willingness to be vaccinated if eligible, a somewhat lower level than the SCZ group in the candidate's study (74%) and considerably lower than the GP group (80%).

Self-efficacy

Self-efficacy was a statistically significant predictor of reported willingness to engage in all protective actions (except hand washing, where no data was collected). Seasonal uptake of vaccination in other studies has been found to be strongly associated with self-efficacy (Gargano et al. 2010; Godin et al. 2010). Even if an individual has high risk perceptions regarding an influenza

outbreak and believes the risk benefit profile of a protective action to be favourable, there appears to still be a need for the belief that they can actually go ahead and carry out the action. This belief is influenced by perceived barriers, which will be discussed in the next section of this chapter.

Risk perception variables as predictors of willingness

Risk perception variables relating to H1N109 were not shown to be as prominent predictors for willingness to adopt protective actions as found in other studies. For example, for both SARS and H1N109, perceived *seriousness* has been found to be linked to willingness to take precautionary measures but in the present study it was not a predictor for any of the interventions (in either the SCZ or GP group). However, for people with schizophrenia perceived personal likelihood of contracting H1N109 did predict willingness to be vaccinated, and perceived overall risk from H1N109 predicted willingness to wear a face mask. In the GP group, people who perceived a substantive overall personal risk from H1N109 were significantly more likely to report being willing to increase hand washing. Interestingly, although for the general public, perceived effectiveness and perceived risk of an adverse reaction influenced willingness to receive a vaccination, they were not predictors for people with schizophrenia for vaccination willingness, despite this group perceiving a higher risk of adverse reactions and more concern about 'catching the flu' from a vaccination.

Temporal factors

In contrast to a survey of the general population in the US (conducted from late April to late May 2009) which found that engagement in precautionary measures against H1N109 decreased over time (Ibuka et al. 2010), the current study did not find *week of participation* to be a predictor of willingness to adopt any of the precautionary measures, despite it beginning in the relatively early stages of the outbreak and extending over a four month period.

Affective factors

For people with schizophrenia, an expectation of feeling afraid in the event of contracting swine flu was found to be an important predictor in reported willingness to adopt all precautionary measures except social isolation. Despite *affective blunting* being a frequent component of the negative syndrome of schizophrenia, emotion still appears to play an important role in decision-making, as it does in the general population. In addition, it is possible that people with schizophrenia may have, as a result of their illness, different thresholds and understanding of fear and depression, compared with people without schizophrenia. Further research into the role of affect in decision-making by people with schizophrenia, controlling for negative symptoms and cognitive function, is warranted. A somewhat surprising result in the thesis study was that predicted affective response was not a robust predictor for willingness in the GP group, being only a weak positive predictor for willingness to wear a face mask. Other studies of the general population have found a correlation between anxiety and willingness to carry out protective

behaviours (Goodwin et al. 2009; Jones & Salathe 2009; Rubin et al. 2009; Lau et al. 2010). However, these studies measured self-reported *current* anxiety rather than *predicted* anxiety in the event of contracting influenza virus.

5.3.9 Limitations

There are several limitations specific to this aspect of the study. *Reported* willingness to engage in a given precautionary measure may not necessarily predict what action is or is not *actually* taken during a pandemic. Therefore, there are limitations in the present study with respect to the evaluation of health *behaviours*, which are more closely related to health outcomes than willingness alone. However, as discussed earlier, there is evidence that risk perceptions, which the present study has examined, do play a role in influencing the relationship between what people say they will do and what they actually do (Weinstein et al. 2007; Eastwood et al. 2010). In terms of affective factors, *predicted* fear or depressed mood in the event of contracting the pandemic virus may not necessarily occur and, therefore, it is the *prediction* that is being measured not *actual* fear or depressed mood. Nevertheless, although this 'predictive' process has a cognitive component, there is likely to also be an affective element that guides it as one contemplates being infected by the circulating virus and experiences an associated affective response. A further limitation of the thesis study involves the social isolation protective measure ("isolating yourself from others if needed"). Although this was intended to denote self-isolation at home, there is possibly some lack of clarity in the wording of the question. It may have been

interpreted as government directed quarantine (e.g. on arrival Australia from overseas), although there was no evidence in the data that is was interpreted this way. In addition, there are different purposes and gains for social isolation that were not detailed in the questionnaire. For instance, social isolation (or 'distancing') with respect to avoiding events or places where there is overcrowding, can result in a gain for a non-infected individual by reducing the risk of exposure to the circulating virus. However, isolating oneself at home when already ill with influenza, results in potential gains for others in the community, by reducing viral transmission. Another limitation was that antiviral medication, which plays a role in both the treatment of influenza as well as prophylaxis, was not included in this study due to concerns about availability and use guidelines. Finally, there are limitations in power, especially with respect to the within-group SCZ analysis and particularly for binary predictor variables.

5.3.10 Practical implications

As discussed in chapter two, vaccination and infection control measures, especially hand washing, can reduce the spread of respiratory viruses, significantly impacting on the trajectory of an influenza pandemic, with benefits for both the individual and the community at large. These protective measures are particularly important for people with schizophrenia, given their vulnerability during a pandemic, as well as with seasonal influenza (as discussed in chapter one). Therefore, given the substantive levels of self-reported willingness to adopt protective measures, if recommended by government authorities,

revealed in the thesis study, it is important that there are clear, timely and practical recommendations from health experts. There is evidence in the literature of the general public's distrust of the news media, perceiving them to have a tendency to exaggerate and sensationalize health threats (Wray et al. 2008). Therefore, well-communicated evidence-based directions from health experts are required to override perceived hyperbole from the media. In view of the disparity between the SCZ and GP groups regarding concern about 'catching flu' from a killed vaccine, education and discussion aimed at modifying any misconceptions about side effects is particularly important for people with schizophrenia. Minor coryza-like symptoms may occur in some people in the days following vaccination. Although it is not 'catching the flu' it may be confused with it. Clarification of this issue may increase uptake rates of influenza vaccination. The provision of posters in waiting rooms at community mental health centres and facilities, hospital wards and in the community generally, may assist with this educative process. As self-efficacy was a consistent predictor of willingness to engage in precautionary activities in both groups, further exploration of this association is a worthwhile consideration in future research because it may affect uptake of protective measures in the community. Perception of barriers is an important aspect of self-efficacy and will be discussed in the next section of this chapter.

5.3.11 Conclusion

The majority of people in both groups were willing to adopt all four protective measures during the influenza pandemic. Participants with schizophrenia

reported that they would be at least moderately willing to be vaccinated (74.3%), isolate themselves (73.2%), wear a face mask (54.9%) and increase hand washing (88.6%) if advised to by government authorities. However, there were statistically significant differences between people with schizophrenia attending a public mental health facility and people without schizophrenia attending a general practice, in their reported willingness to adopt protective measures during a pandemic influenza. People with schizophrenia were less likely to be willing to receive a vaccination and to isolate themselves compared with people without schizophrenia attending a general practice. Both groups reported high levels of willingness to increase hand washing. These findings in the thesis study need to be taken into account in preparedness and response planning for a future pandemic in Australia, particularly given the vulnerability of people schizophrenia to adverse clinical outcomes from influenza and pneumonia. Education about the risk benefit profile of receiving an influenza vaccine, including correction of any misconceptions about potential side effects from a vaccination, needs to be provided by health services and clinicians. Especially in light of the high levels of willingness revealed in this component of the thesis study, hand washing as a simple, inexpensive and effective protective measure should be a core focus in public health messaging in general, but with added emphasis during a pandemic, when risks are heightened. Given that self-efficacy was a predictor of willingness for vaccination, self-isolation and wearing a face mask for people with schizophrenia, exploration by health care workers of their patients' perceived barriers or difficulties in carrying out these protective measures, is likely to be helpful.

5.4 Perceived barriers to adopting protective measures during a pandemic influenza

5.4.1 Introduction

In order to develop strategies to mitigate the potential negative impact of an influenza pandemic on people with schizophrenia, it was seen as important to explore their reasons for reluctance or refusal to adopt protective measures. Perceived barriers influence self-efficacy, which, is a determinant of health behaviour. Self-efficacy was found to be a strong predictor of willingness to adopt protective measures in the thesis study, for both groups of participants. As described in chapter four, data were gathered, using open-ended questions, on what participants perceived as difficulties in carrying out each of the four protective measures. Themes were identified and data were coded numerically. Results are presented followed by a discussion of perceived barriers.

5.4.2 Vaccination

Participants in the study were asked:

"What might be difficult for you about having a vaccination? Please name three things".

Responses from both the SCZ and GP groups were assigned to fifteen identified *perceived barrier* themes, including a "no difficulty" category (Chart 5.1). Table 5.4.1 provides illustrative examples of responses forming the main themes.

Table 5.4.1 Perceived barriers to vaccination: sample responses and identified themes

IDENTIFIED THEME	RESPONSES	
	SCZ	**GP**
Side effects	• "Side effects" • "Reaction to it" • "Potential adverse reaction"	• "Side effects" • "Possible side" • "Adverse side effects"
Cost	• "Cost" • "Paying for it" • "Cost, would like government to pay"	• "Cost" • "Price" • "Money"
Transport to a clinic (to receive vaccination)	• "Transport to get there" • "Transportation to clinic" • "Getting to it"	• "Transport/location" • "Location" • "Location in hospital or GP"
Dislike of needles	• "Hate needles" • "I don't like nedels (*sic*)" • "Don't like injections"	• "Hate needles" • "I hate needles" • "Dislike of needles"
Time	• "Time" • "Time to do it" • "Time to have it"	• "Time" • "Time Time Time" • "Time to get it"
Availability of vaccine	• "Availability of vaccine" • "Is it available"	• "Vaccine availability" • "Availability"
Organizing the vaccine	• "Organizing it" • "Organizing to get it"	• "Organizing it" • "Getting organized
Availability of appointment	• "Nothing but getting a drs (*sic*) appointment" • "Finding a doctor"	• "Availability of appointment" • "Unavailability of doctors"
Pain	• "The needle pain" • "The pain of injection"	• "Pain" • "The pain"
Information issues	• "Learning about it" • "I would need advice"	• "Lack of proper information " • "No information"
Vaccine is not needed	• "I don't easily get the flu" • "Stay fit, keep a personal hygene (*sic)* standard"	• "I don't need it – never sick" • "I don't think I need the vaccine"

Chart 5.1 Perceived barriers to vaccination
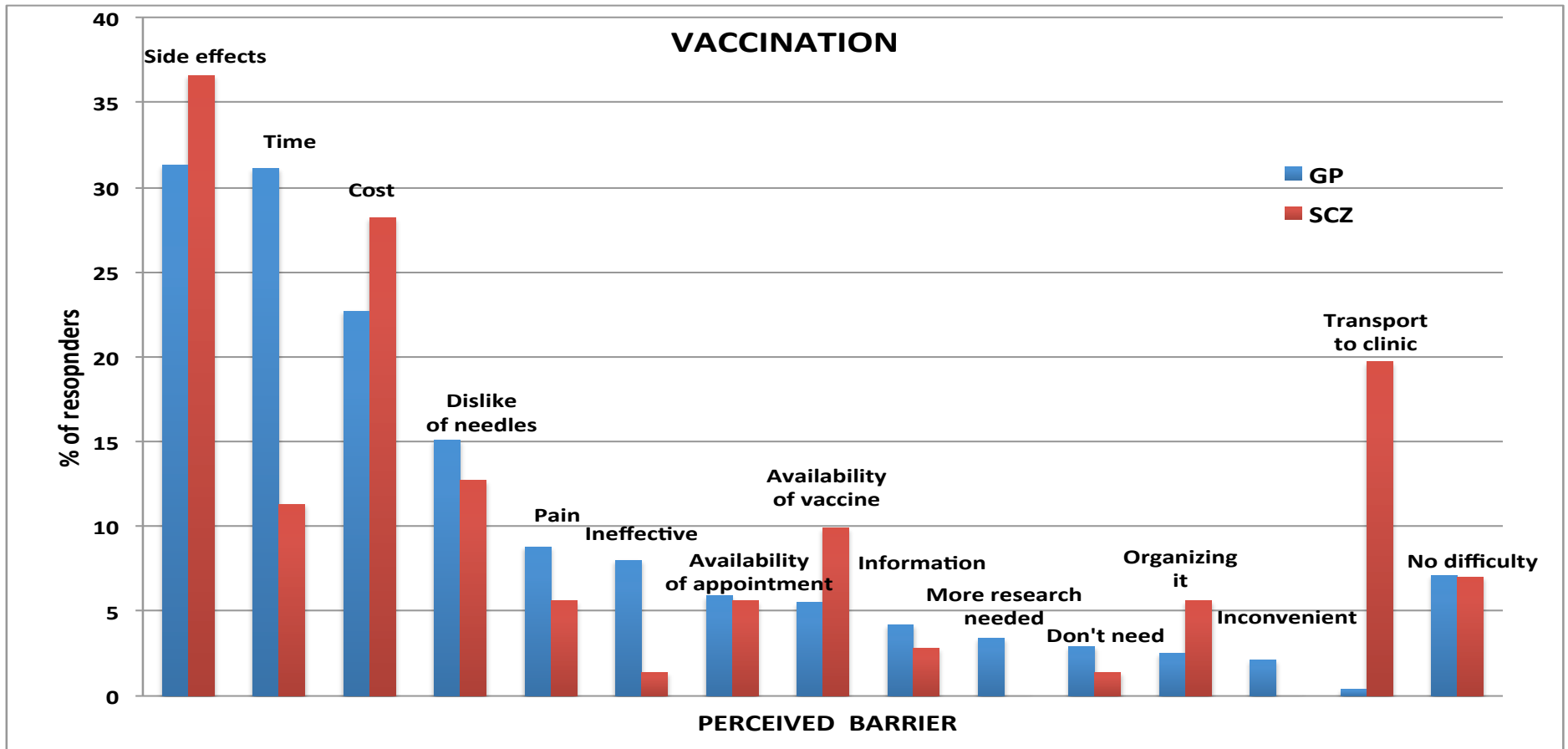
The commonest perceived barrier to having a vaccination, in both groups, was concern about side effects, with 36.6% of participants in the SCZ group and 31.3% in the GP group identifying it as a difficulty. As shown in Chart 5.1, the second and third most commonly perceived barriers for the GP group were time (31.1%, almost equal to side effects) and cost (28.0%). However, for the SCZ group, time appeared to be a much less important barrier (11.3%). The second and third commonest perceived barriers for the SCZ group were cost (28.2%) and transport to a clinic (19.7%) where the vaccination could be administered. Dislike of needles was the fourth most commonly cited barrier for both groups, with 15.1% in the GP group identifying this as a difficulty and 12.7% in the SCZ group.

Less frequently identified barriers by both groups included vaccination pain, vaccine perceived as ineffective, difficulty getting an appointment to receive a vaccination, availability of the vaccine, inadequate information on the vaccine, more research needed on the vaccine, no need for a vaccination, organizing it, and inconvenience. These were all identified by less than 10% of participants in both groups. About 7% of participants in both groups indicated that they were not aware of any difficulties in having a vaccination.

5.4.3 *Isolation*

Participants in the study were asked:

"What might be difficult for you about isolating yourself from others? Please name three things".

Table 5.4.2 Perceived barriers to social isolation: sample responses and identified themes

IDENTIFIED THEME	RESPONSES	
	SCZ	GP
Loneliness / Missing social contact	• "Lonliness (*sic*)" • "Missed loved ones" • "Lonely" • "No one to talk to"	• "Socializing with others" • "Person to person interaction" • "Social – seeing friends" • "Missing catching up with friends and family"
Accessing food and groceries	• "Shopping (food)" • "Grocery shopping" • "Food"	• "Buying food" • "Buying groceries" • "Getting essentials – food etc"
Boredom	• "Bordom (*sic*)" • "Boredom"	• "Boring" • "Get bored"
Attending work / study commitments	• "Missing work" • "Would want to go to work/study"	• "Work commitments" • "Missing UNI"
Interfering with leisure pursuits	• "Cycling" • "Dining in public"	• "Walking the dog" • "No sport"
Accessing medical needs	• "Accessing my medication" • "Medication"	• "Seeking medical assistance" • "Need for med/dental treatment"
"Other"	• "Clostrophobia (*sic*)" • "Getting in my own head"	• "Cabin fever depending on length of isolation" • "Keeping people out"

Responses from both the SCZ and GP groups were able to be assigned to ten main *perceived barrier* themes, including a "no difficulty" category (Chart 5.2). A category "other" was used for multiple disparate perceived barriers, each of which comprised less than 2% of responses in each group. Table 5.4.2 provides illustrative examples of responses forming the main themes.

Chart 5.2 Perceived barriers to isolation

ISOLATION

% of responders — PERCEIVED BARRIER

Legend: GP (blue), SCZ (red)

Categories: Loneliness / missing social contact; Attending work or university; Attending to child, family or carer duties; Accessing food or groceries; Boredom; Missing leisure pursuits; Depressing; Shared accommodation; Accessing medical needs; Other; No difficulty
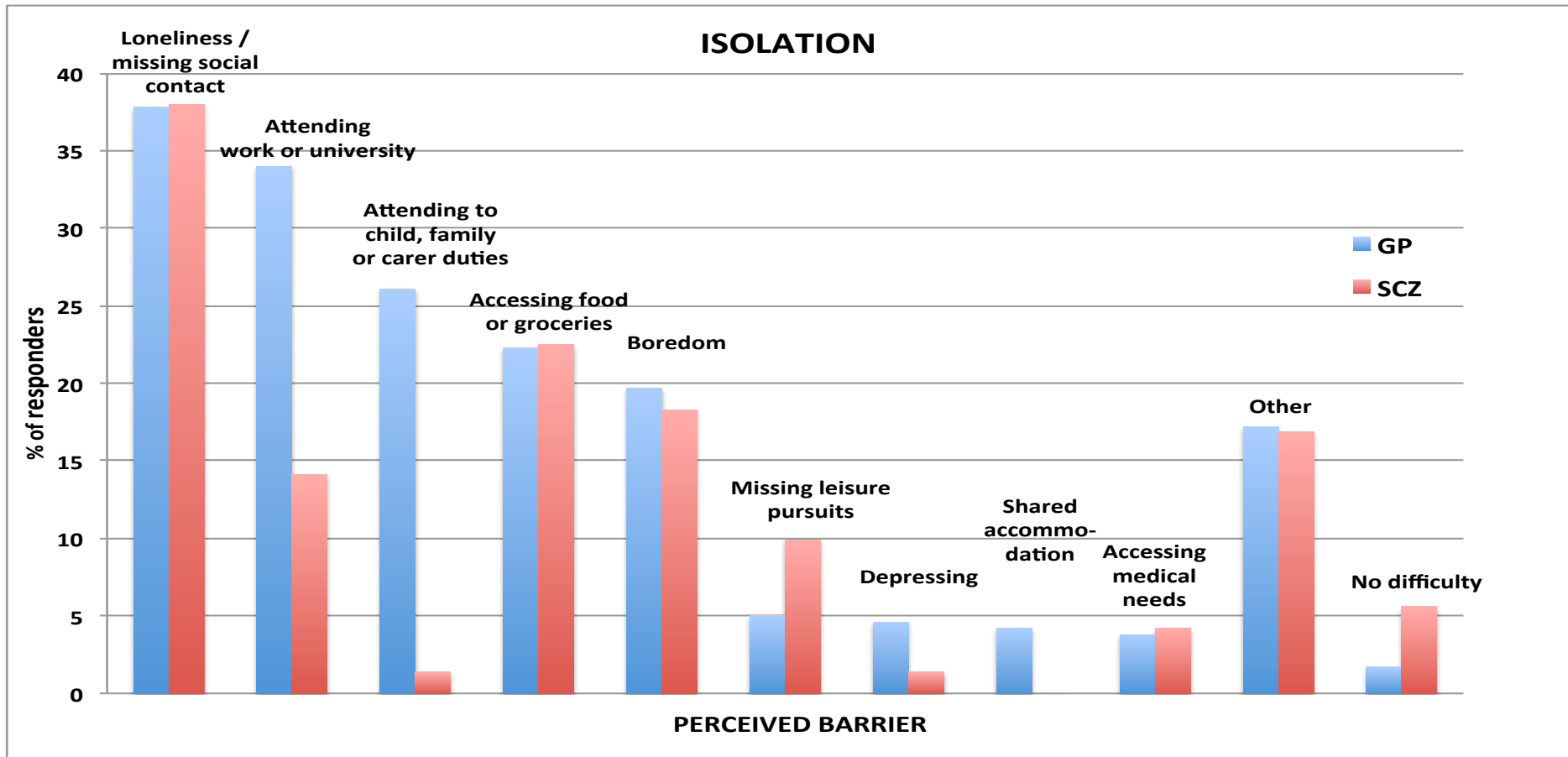
The commonest perceived barrier to isolating oneself, in both groups, was loneliness and missing social contact (SCZ group 38%, GP 37.8%). For the GP group, the next most commonly perceived barriers were attending work or university (34.0%), and attending to child, family or carer duties (26.1%). However, for the SCZ group, the second and third most commonly perceived barriers were accessing food or groceries (22.5%) and boredom (18.3%) respectively. As shown in Chart 5.2, other perceived barriers in both groups included missing leisure pursuits, isolation seen as depressing, and difficulty accessing medical needs (such as consulting a doctor or buying medications). Shared accommodation was seen as a barrier by some (4.6%) in the GP group but did not appear to be relevant to the SCZ group. No difficulty with isolation was reported by 1.7% in the GP group and 5.6% in the SCZ group.

5.4.4 *Face mask*

Participants in the study were asked:

"What might be difficult for you about wearing face mask? Please name three things".

Responses from both the SCZ and GP groups were able to be assigned to eleven main *perceived barrier* themes (Chart 5.3). Table 5.4.3 provides illustrative examples of responses forming the main themes.

Table 5.4.3 Perceived barriers to wearing a face mask: sample responses and identified themes

IDENTIFIED THEME	RESPONSES	
	SCZ	GP
Appearance / stigma	• "Appearance" • "That it looks bad" • "Being ostracized" • "Looks silly" • "Standing out"	• "How it looks" • "Stigma" • "I would look different from other people" • "Looks ridiculous"
Uncomfortable	• "Uncomfortable" • "Discomfort"	• "Discomfort" • "Cutting into my ears"
Difficulty breathing	• " Breathing" • "Can't breathe"	• "Making breathing difficult" • "Breathing (mouth breather)"
Ineffective	• "Pointless" • "Air gaps – useless" • "It still doesn't stop risk"	• "Thought of lack of effectiveness" • "No that effective"
Access / cost	• "Obtaining one!" • "Getting more than one" • "Cost"	• "Access to mask" • "Able to buy them" • "Cost"
Difficulty communicating	• "Hard to talk" • "Communication" • "Speech"	• "Can't talk over the phone" • "Talking in job" • "Inhibit communication as barrier (physical)"
Difficulty eating and/or drinking	• "Eating drinking" • "Difficulty eating" • "Drinking water"	• "Difficult to eat" • "Drinking coffee" • "Eating drinking"
"Other"	• "An eary (*sic*) feeling" • "Scar"	• "Glasses fogging up" • "It will cause a pimple on my face"

The category "other" contained multiple disparate perceived barriers, each of which comprised less than 2% of each group. Some of these included:

- "It will cause a pimple on my face" (GP)

- "An eary (*sic*) feeling" (SCZ)

- "Glasses fogging up" (GP)

Chart 5.3 Perceived barriers to wearing a face mask
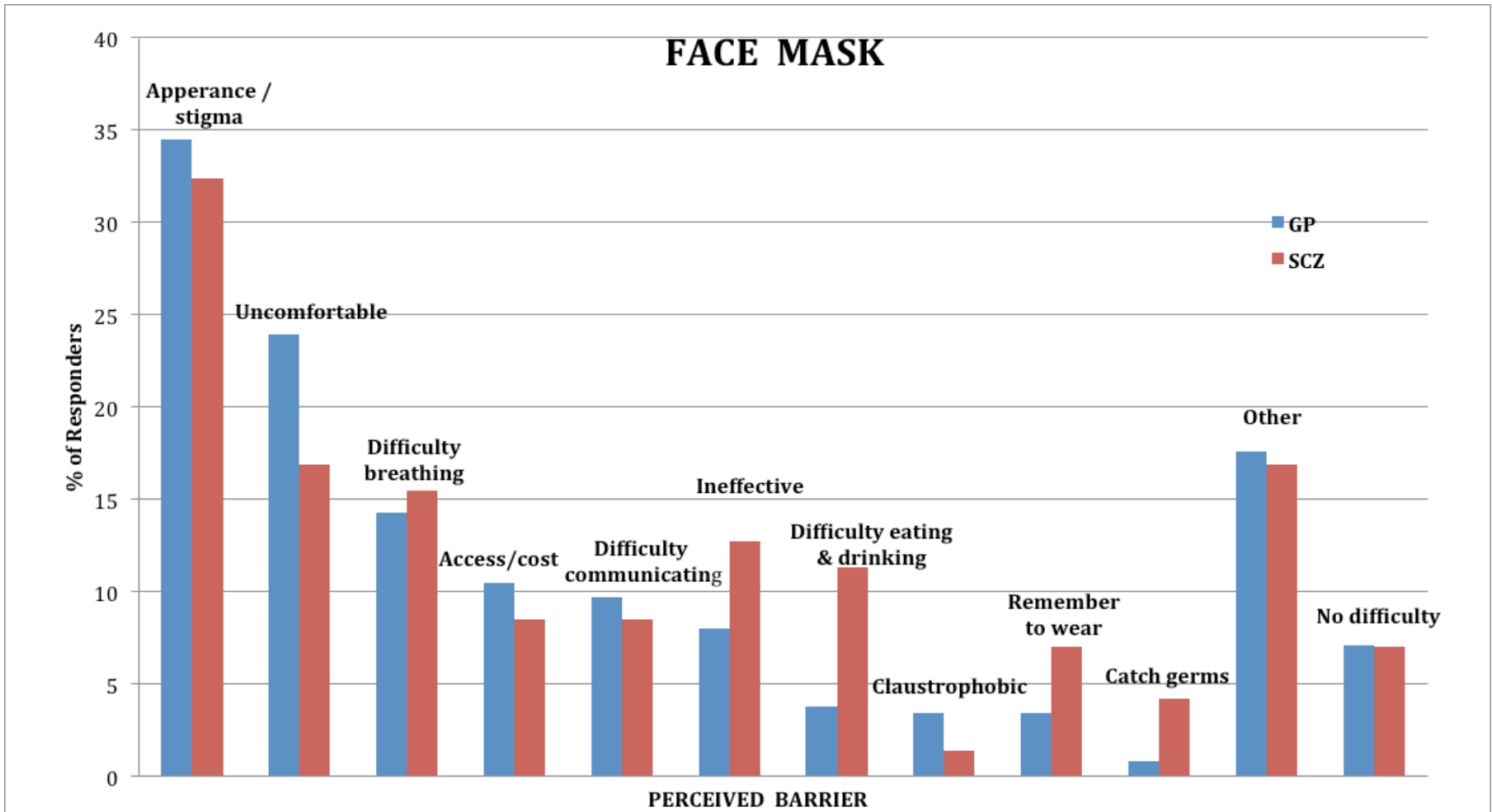
Overall there were similarities in perceived barriers to wearing a face mask between the SCZ and GP groups. In both groups, the three commonest perceived barriers were appearance/stigma, finding a mask uncomfortable, and difficulty breathing (Chart 5.3). "Other" barriers included access/cost, ineffectiveness, difficulties eating and drinking, claustrophobia, remembering to wear the mask and "catching germs" from it. No difficulties were identified in 7% of both groups.

5.4.5 *Hand washing*

Participants in the study were asked:

"What might be difficult for you about washing your hands more frequently? Please name three things".

Responses from both the SCZ and GP groups were assigned to eight main *perceived barrier* themes, including a "no difficulty" category (Chart 5.4). Table 5.4.4 provides illustrative examples of responses forming the main themes.

By far the commonest perceived barrier for increased hand hygiene by both groups (Chart 5.4) was having access to hand washing facilities (GP group 31%, SCZ group 29.8%). For the GP group the second and third most commonly perceived barriers were remembering to do it (14.1%) and time (8.5%). In contrast, for the SCZ group, concern about skin

Table 5.4.4 Perceived barriers to hand washing: sample responses and identified themes

IDENTIFIED THEME	RESPONSES	
	SCZ	**GP**
Access to facilities	• "Can't always find a bathroom" • "Access to facility when away from home" • "Not In place where you can wash hand (*sic*)" • "Availability"	• "Access to facilities" • "Not been (*sic*) near water" • "No facilities" • "Near tap/bathroom"
Skin irritation / problem	• "Dermatitis" • "Dry skine (*sic*)" • "Rash" • "Cracked skin!"	• "Cause skin irritation" • "Dry skin" • "Some allergy to soap" • "Chapped, bleeding + open skin on hands as a result"
Time	• "Time consuming" • "No time" • "Finding time"	• "Time" • "Time Time Time" • Time consuming"
Remembering	• Remembering" • "Remembering to do it" • "Forgetting"	• "Remembering" • "Remembering to do it" • "Forgetfulness"
Waste of resources	• "Using more water wastage" • "Waste of resources"	• "Drought" • "Wasting water"
"Other"	• "Filthy toilets" • "Diseased bathrooms"	• "I'm a carpenter…They are filthy all day anyway" • "Listening to the 'she'll be right' voice"

irritation (15.1%) and time (14.7%) respectively were the next most commonly

cited barriers. Additional perceived barriers in both groups included that it was

a waste of resources, inconvenience and laziness. No difficulty was cited in

16.9% of participants in the GP group and 19.7% of those in the SCZ group.

Chart 5.4 Perceived barriers to increased hand washing
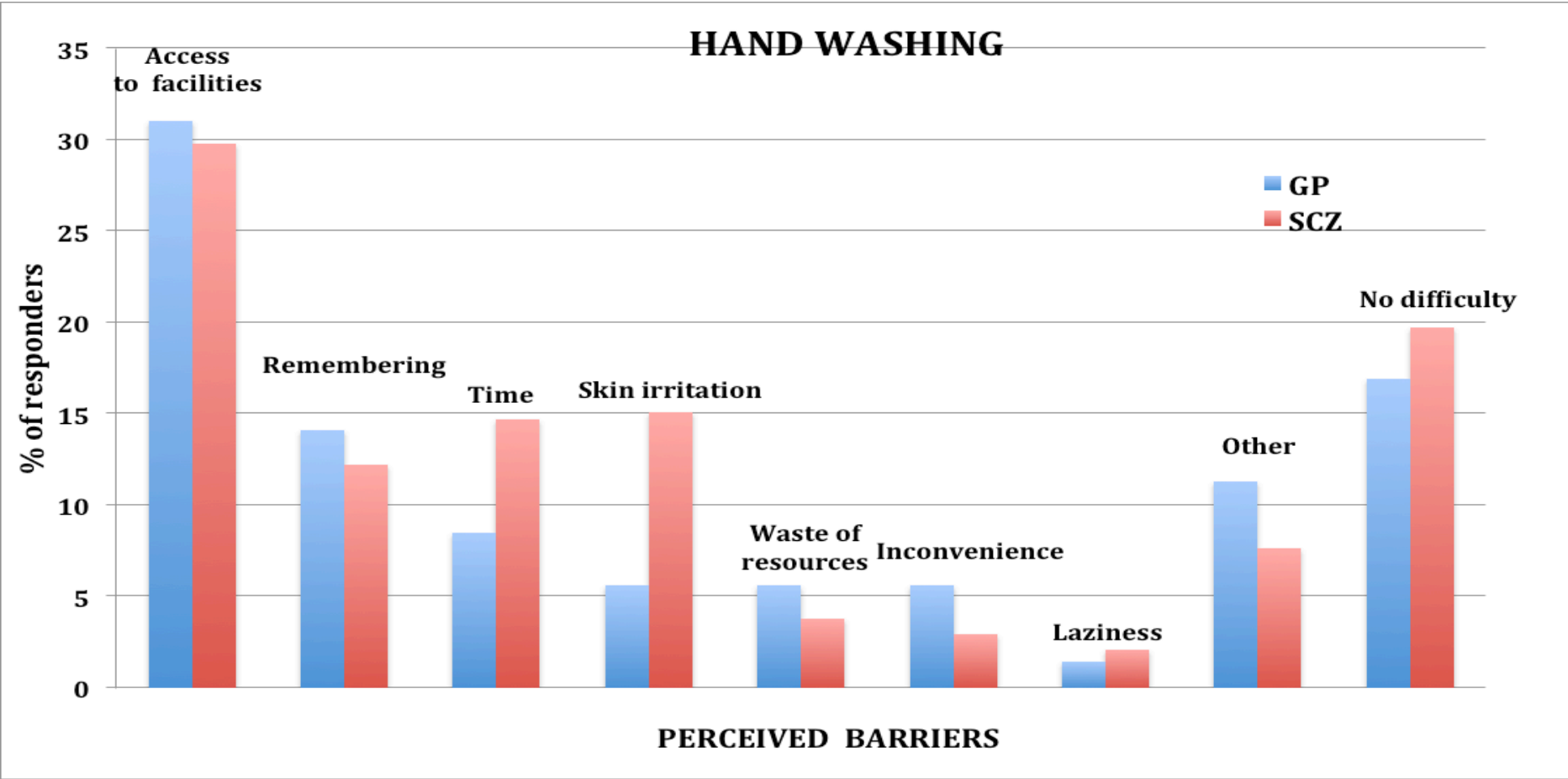
5.4.6 Discussion

Vaccination

Just over one in three participants in the SCZ group, and just under one in three in the GP group, cited "side effects" as a barrier for being vaccinated. The prominence of "side effects" as a perceived barrier is consistent with studies in the general population, as discussed in chapter two. Given that, in general, the side effects from influenza vaccinations are mild, education about typical minor adverse reactions to a vaccination appears to be an important factor in encouraging people to take up this protective measure. As noted in chapter five, a significant number of people in both groups believed that it was possible to "catch the flu" from a vaccination. Regression analysis revealed that this misconception was statistically significantly higher in those with schizophrenia. Exploring and clarifying this issue may increase uptake rates of vaccination in people with schizophrenia. Similarly, there were substantial differences between the two groups for transport to a clinic as a perceived barrier. Approximately one in five nominated this as a barrier in the SCZ group compared with a negligible proportion (< 1%) in the GP group. Again, this has practical implications. Assistance with transport to a clinic (or possibly community mental health centre), or administration of the vaccination by a mental health nurse during a home visit, may increase the uptake rate in people with schizophrenia. Cost was important in both groups, but particularly for people in the SCZ group. Given the socio-demographic differences between the two groups, this is unsurprising. Assistance with funding may be a strategy to improve uptake. Finally, although time was an important factor for

those in the GP group, equaling concerns about side effects, it was much less so for participants with schizophrenia. One could speculate that this may again be due to socio-demographic differences, with a lower number of people with schizophrenia being employed or having family or carer duties.

Isolation

Close to 40% of participants in each group perceived loneliness and a sense of missing social interaction, as a barrier to self-isolation. This was the most commonly identified barrier for all of the four protective measures, for both people with schizophrenia and people attending a general practice. Again, It is useful to view this finding in the context of the relevant socio-demographic factors. Many people with schizophrenia are socially isolated, do not have a partner and are marginalized in society. In the present study, about 90% of people in the GP group lived with others, whereas about a third of people with schizophrenia lived alone. Only about one in five people with schizophrenia were in employment, compared over 90% in the GP group. As few as 5.6% of participants in the SCZ group reported that there were children in the household, compared with 43.7% in the GP group. These data indicate that for most people in the GP group, isolating at home may not imply complete absence of contact with family or others whom they are living with. There may be some social interaction even if they are in a separate room or trying to keep at least one metre away from others (as advised by the AHMPPI). However, for the third of people with schizophrenia living alone, home isolation may impose significantly more disruption to their social connectivity. It could also be

argued that living alone may amplify the importance of being able to meet with friends either at home or outside the home. The low proportion of people with schizophrenia in employment is also relevant in terms of social contact. Although earning an income is one benefit of having a job, social contact and inclusiveness is also an important gain. In addition, there is evidence that employment improves self-esteem, reduces dependency, alleviates or distracts from symptoms and improves overall quality of life (Crowther et al. 2001). Given the socio-demographic differences between the two groups mentioned above, it is not surprising that interruption to attendance at work or university, or to family or carer duties, were more frequently cited as barriers in the GP group. Concerns about the need to buy food and groceries were frequent in both groups, as were concerns about being bored. Despite 'asociality' being included as a component of the 'negative syndrome' of schizophrenia, the findings in this section of the study reflect that people with schizophrenia have important social needs, as do people attending a general practice. For some people, the thought of social isolation at home may be confronting, further compounding a pre-existing social disconnectivity. As such, health services may need to provide extra psychological support for vulnerable people during this period. Only a small proportion of both groups (< 6%) believed that there would be no difficulties in isolating themselves.

Face mask

There were very strong similarities between the two groups for perceived barriers to wearing a face mask, with the rank order of the three most cited

barriers (appearance/stigma, uncomfortable, difficulty breathing) being the same. This is at variance with a study in the general population discussed in chapter two (MacIntyre et al. 2009), where the most commonly cited barrier was discomfort. With approximately one in three participants in each group being concerned about their appearance if a mask were worn, further exploration and evaluation of this perceived barrier might be useful, in order to know how to reduce stigma and/or self-consciousness, and to increase the uptake of this protective measure. This may be particularly true for people in the SCZ group, where significant levels of stigma related to having a mental illness, already exist. A data extract relating to perceived difficulties for wearing a face mask (Table 5.4.3) from a participant with schizophrenia epitomizes this, "Being ostrasized (*sic*)". The different kinds of masks that have been used in an influenza pandemic have been described in chapter four. The comments in this qualitative part of the study suggest that participants did interpret face mask to mean surgical face mask. "Ineffectiveness" was the fourth most common reported barrier in participants with schizophrenia and sixth in rank order for people attending a general practice. Identification of limitations in effectiveness for wearing a face mask is consistent with expert opinion. For instance, as discussed in chapter two, the CDC recommended wearing a face mask during the H1N109 pandemic only for those who were in a vulnerable (i.e. high risk) group and could not avoid a crowded community setting, and for vulnerable care-givers to an individual infected with H1N109. However, together with social isolation / distancing and hand hygiene, it was part of the SARS infection control offensive that reduced laboratory confirmed viral

infection rates in the general population of Hong Kong by over 80% (Lo et al. 2005; Collignon & Carnie 2006). As discussed in chapter two, although face masks decrease the quantity of inhaled virus-laden droplets, their key mode of efficacy may be reduction of self-inoculation through reducing the ability of a person exposed to a respiratory virus to directly touch their nose or mouth (Collignon & Carnie 2006).

Hand washing

Although many of Ignaz Semmelweis's contemporaries in the 1800s were slow to accept the importance of hand washing despite his demonstration that it dramatically reduced puerperal fever and associated maternal mortality rates, it now has a well deserved central place in infection control. Given the simplicity and effectiveness of hand washing in reducing the transmission of respiratory viruses, an understanding of perceived barriers to increased hand washing is particularly important. "Access to facilities" appears to be a key issue, with close to one in three participants in each group citing it as a barrier. A practical strategy to circumvent this frequently identified obstacle to increased hand washing may be the use of alcohol-based antiseptic gels. These have been shown to be highly effective, are relatively inexpensive and do not require water for their use. "Remembering" was also similar in frequency in the SCZ and GP groups, with about 13% in each group citing it as a barrier to increased hand washing. Well-placed reminder posters in public places such as shopping centres, schools, and hospitals may provide assistance in overcoming this barrier. Interestingly, although for vaccination

"time" was more frequently identified as a barrier for people in the GP group compared to those in the SCZ group, the reverse was true for hand washing. As in studies in the general population (discussed in chapter two), members of both groups cited concerns about skin irritation. Provision of low allergenic soaps or gels may be of assistance with respect to this barrier. It was encouraging to note that "no difficulty" was identified by about 20% of each group.

5.4.7 Conclusion

Significant perceived barriers exist for each of the protective measures for both people with schizophrenia and people without schizophrenia attending a general practice. Although there are some similarities between the groups in how they perceive barriers, there are also substantive differences, which are likely to reflect *socio-demographic* disparities between the two groups of participants. Being unemployed, living alone, not having children in the household, and having lower educational attainment are all likely to have impacted on perceived barriers. Obstacles frequently identified by people without schizophrenia, such as needing to attend child, family and carer duties or to attend work or university, were considerably lower in frequency for people with schizophrenia, whereas cost of purchasing a vaccination and difficulties with transport to a health facility to have it administered, were significantly greater. Assisting people with schizophrenia (as well as people in the general population) to overcome perceived barriers may increase self-efficacy and the uptake of protective measures during an influenza pandemic. Challenges may

exist regarding encouragement of people with schizophrenia to wear a face mask given that appearance/stigma was the most frequently cited barrier and that significant stigmatization of mental illness is still present in our society. A key strategy for increased hand hygiene in the event of a pandemic may be education and encouragement to use antiseptic gels, given that lack of washing facilities was the most frequently cited barriers for increased hand washing in both groups.

CHAPTER SIX

QUALITATIVE STUDY WITH IN-DEPTH INTERVIEWS

6.1 Introduction

As described in Chapter three, the thesis research project endeavors to increase and enrich an understanding of how people with schizophrenia: obtain information on influenza outbreaks; perceive risks associated with pandemic influenza; and view protective measures against influenza, including their willingness to adopt them. To assist in achieving these aims, the candidate carried out a qualitative study consisting of eleven in-depth semi-structured interviews with individuals with schizophrenia. A qualitative design was chosen in order to provide richer, more detailed and personalized data, seeking subtleties and complexities that may have been undetected by the 2009 thesis cross-sectional survey. In addition, while the survey enquired about how health information in general is obtained, the qualitative study targeted health information sources relating specifically to influenza, both seasonal and pandemic.

6.2 Research questions

Arising from the research aims, and not (fully) addressed by the 2009 thesis survey, are the following research questions driving the qualitative study.

(1) What is the *illness experience* of influenza for people with schizophrenia?

(2) How do people with schizophrenia *seek information* about *influenza*?

(3) How did people with schizophrenia become aware of the 2009 swine influenza pandemic and what is their recollection of their *risk perception* of it?

(4) How do people with schizophrenia view *protective measures* against influenza?

(5) How do people with schizophrenia perceive the threat of a future pandemic influenza, including bird flu?

(6) What information about influenza do people with schizophrenia believe is important for the public to know?

6.3 Sample

The candidate used a purposive sample aimed at maximizing diversity in the recruitment of potential participants, in terms of socio-demographic factors (Table 6.1). Six men and five women participated in the study. Ages ranged from 25 to 55. Two were in full-time employment, one in part-time work, one did causal work, and five were unemployed. Four participants lived alone. The remainder lived with their family, including a participant living with her daughter, who was under the age of ten. The candidate recruited five participants who had been involved in the 2009 cross-sectional study, and six further participants. All were patients attending and engaging in mental health care at a community health centre.

Table 6.1 Participants: de-identified names and demographic features

Name (de-identified)	Age	Gender	Employment status	Lives with
Hugh	25	Male	Casual work	Sibling
David	29	Male	Full-time employment	Alone
Alan	35	Male	Part-time work	Parents, sibling
Martin	35	Male	Unemployed	Alone
Amy	36	Female	Unemployed	Sibling
Ronda	42	Female	Maternal duties (no paid employment)	Daughter (aged <10)
Nigel	46	Male	Full-time work	Family
Tina	47	Female	Unemployed	Mother
Angus	54	Male	Unemployed	Alone
Marnie	55	Female	Unemployed	Alone
Samantha	55	Female	Part-time student	Parents

With regards to the participants who had been involved in the 2009 study, the recruitment process consisted of sending a letter of invitation (Appendix 10) and information brochure describing the study (Appendix 11). All of these participants had an established diagnosis of schizophrenia. The candidate then made a subsequent follow-up phone call to ascertain whether they were interested in, and willing to be, involved in the study. Following this, other patients with an established diagnosis of schizophrenia attending a community health centre were provided with an information brochure about the study and

invited to participate. A further six patients expressed their willingness to be involved. One male patient, who had been invited to be involved in the study, initially agreed but subsequently thought he would not be able to attend. However, he later discovered that he was able to participate after all, and, therefore, was included in the study, bringing the sample size to eleven.

6.4 Procedure

Semi-structured, in-depth face-to-face interviews based on a topic guide (Appendix 12) were conducted by the candidate with eleven patients individually, to enable a detailed exploration of their views, experiences and perspectives, using a flexible and responsive conversational approach. The interview setting was a standard interview room in a community mental health building. These rooms are soundproof, and clinical and administrative staff present in the community health centre were aware not to interrupt the interviews (except in the case of emergency).

A priori, an interview duration of 30-60 minutes was anticipated. However, the interviews ranged from 18-40 minutes. The interviewer, although encouraging participants to express their perspectives and feelings freely, exercised care and sensitivity, guided by his clinical experience, not to exert undue pressure on patients in this regard. The candidate took handwritten notes of the dialogue during the interviews, and transcribed these notes onto a word document within 24 hours of the interview. Initially the candidate had

considered audio-recording the interviews. However, prior to establishing the research project, the candidate had informal discussions with patients with schizophrenia, and clinicians, at the community health centre, which revealed that audio-recording had the potential to make patients, potentially in the sample frame, feel uncomfortable. In addition, the ACT Health Ethics Committee expressed concerns about inducing "feelings of paranoia in the study population". Therefore, the candidate decided not to proceed with this, but rather to record the interview with handwritten notes on prepared topic guide stationary with ample spaces for writing.

Each interview began with an expression of appreciation to the interviewee for participating in the study, and with a reiteration of the chief aims of the study (outlined in the information brochure). Participants were reminded that the interviewer would be taking handwritten notes during the interview if they had no objections to this, and that the interview could last up to 60 minutes. Participants were asked to read through the consent form and sign it, if they had no objections, and to feel free to ask any questions prior to beginning the interview. Immediately before commencing each interview, the researcher explained to participants that open, candid, "natural" responses were being sought, that there were no "right or wrong answers", and that the interviews were about their views not those of the interviewer.

6.5 Ethics

Ethics approval was obtained from both the Australian National University, and ACT Health Human Research, Ethics Committees (Appendix 13) and written informed consent was obtained from participants. Participants were informed both verbally and on the consent form that involvement in the study was purely voluntary and that they could cease their involvement in the study at any time. They were also advised that involvement in the study would not interfere with their clinical care in any way, or incur any costs. The consent form (Appendix 14) provided the contact number of the candidate in case a participant experienced distress or a problem they believed was connected with the research project and wished to discuss it. It also included contact details of a representative of the ACT Human Research Ethics Committee, in the event that the participant chose not to speak with the researcher.

The information brochure provided a summary of the aims of the research study and what participation in the study would involve. It also included contact details of a crisis counseling service in case involvement in the study caused a participant to feel distressed or at risk in any way.

A financial award ($AU30.00) was offered in recognition of the time, effort and travel costs for the participant. The ethical rationale for this has been discussed earlier on pages 160-161.

6.6 Instruments

An interview topic guide (Appendix 11) was formulated in order to provide a *framework* for the qualitative data collection, and to ensure that a similar range of topics was discussed with each participant. The content of the interview guide correlates with each of the research questions described earlier.

Although this instrument has value in providing a degree of structure for the dialogue, it was viewed as important for the interview process to remain flexible and responsive, not adhering over-rigidly to the questions in the topic guide. For instance, if there were the need to seek clarification regarding a response, the required additional questions would be asked in order to achieve this. As Braun and Clarke (2006) point out, analysis begins during the face-to-face interview. As such, the candidate focused an awareness on factors suggesting potential relevant themes, including: frequency of mention of a given perception, view or experience during a participant's interview; how many interviewees shared a given view (i.e. how widely a given view was held); the intensity of views held (i.e. how passionate a view was held or how much it was stressed by the interviewee) based on observation during the interview of the participant's affective response including tone of voice, facial expression, body language, and eye contact; the specificity of views held (i.e. whether interviewees' views were based on, or reflected, specific personal experiences and feelings or whether they were an expression of a more generic view); and whether what was said by participants reflected an

underlying *latent* idea, assumption or conceptualization, rather than a purely *semantic* (i.e. explicit or surface) meaning.

6.7 Analysis strategy

The qualitative data analysis software NVivo (version 10.0.3 for Mac) was used to assist in data analysis. Data were examined using both a preliminary *framework approach* based on the topic guide, to provide an overview of the predetermined issues outlined above, and a more detailed "data-driven" **thematic analysis** approach, examining for patterned responses and meanings throughout the entire data set (Braun & Clarke 2006).

The process of **thematic analysis** used by the candidate involved working through the six phases identified by Braun and Clarke (Table 6.2). The candidate immersed himself in the depth and breadth of the data through three thorough initial readings of all in-depth interview transcripts, noting down in the "Memo" resource of NVivo initial ideas regarding meaningful and relevant aspects of the data. On the fourth reading of the transcripts the candidate recorded chosen extracts and assigned initial codes to each extract (Appendix 15), in the "Nodes" function of NVivo. As recommended by Braun and Clarke, the candidate coded for as many potential themes/patterns as possible, on the rationale that they may be found to be relevant in the later phases of data analysis and, if not, could easily be removed. These codes were then collated, and repeated codes removed, producing a working list of codes (Appendix 16).

Next, the data extracts and applied codes were examined in the search for themes. Identified themes were subsequently reviewed and refined. An overview of the final main themes and subthemes is shown in Figure 6.

Table 6.2 Phases of Thematic Analysis (adapted from Braun & Clarke 2006)

Phase	Description of process
1. Familiarization with the data	Reading and re-reading the transcribed data in an active way searching for meanings and patterns; noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set; collating data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes	Checking that themes work in relation to coded extracts, generating a thematic "map" of the analysis
5. Defining and renaming themes	Ongoing analysis to refine specifics of each theme and overall story the analysis tells; generating clear definitions and names for each theme
6. Producing the report	Selection of vivid, compelling extract examples; final analysis of selected extracts, relating analysis to research question and literature

6.8 Results and discussion

6.8.1 Framework approach

This provides a general overview of responses, within the framework of the interview topic guide.
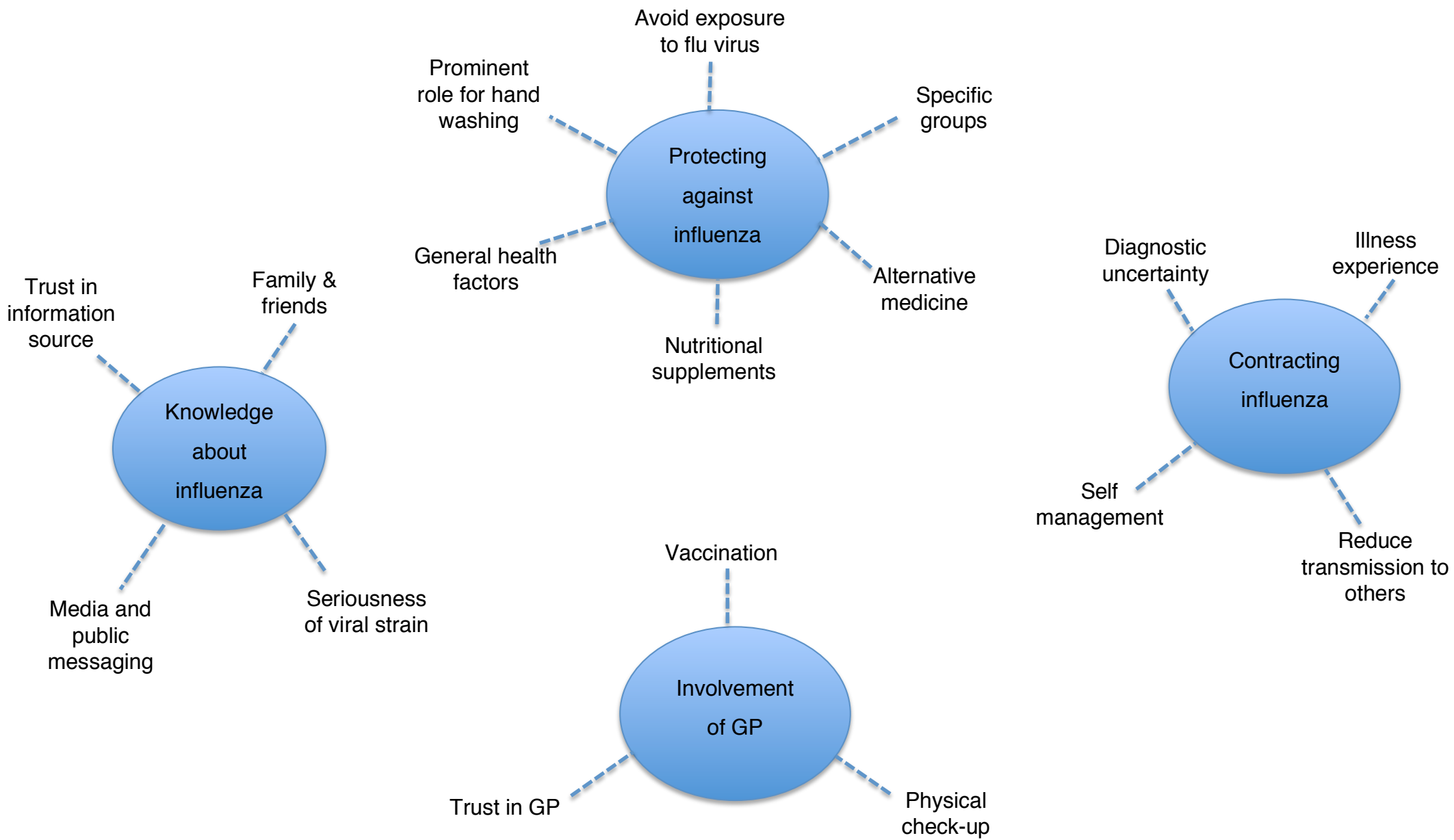
Figure 6 Thematic Map: Themes with associated subthemes

Question 1

All participants except one recollected having contracted influenza (or influenza-like symptoms in the case of one participant) at some point in their lives. However, there was a large range in terms of frequency of influenza illness recalled. Four participants indicated that they had had influenza only once. In contrast to this, two reported experiencing influenza yearly. Subjective experience of "illness" again varied considerably, ranging from "Wasn't very sick with it" (Angus) to "I thought I was dying" (Martin).

When asked whether they consulted a doctor at the time of having influenza, the number of responses in the affirmative (five) was comparable to the number of negative responses (four). Of those who did not see a doctor there were diametrically opposed reasons given for this, with some participants believing they were "*not sick enough*" to warrant consulting a doctor, and others finding themselves "*too sick to get out of bed*" in order to travel to a doctor.

Most participants (seven) appeared to value their GP as an information source for obtaining more knowledge about influenza. This included seeking information on both a prevailing influenza as well as influenza in general. However, answers weren't restricted to doctors as a health information source. As in the thesis survey (for health information in general), there were many other information sources nominated, including: a medical journal at the National Library; a medical dictionary; an official Internet website; "people at

work"; treating psychiatrist; television ("they have a special section on flus as part of the news"); family and/or friends; and a government-run 'walk-in centre'. Interestingly, no interviewees spoke of using the radio or newspaper to specifically *seek* information on influenza (although several had heard about swine flu and/or bird flu through these media).

Question 2

All but one participant recalled hearing about swine flu in 2009, and seven of these had heard about it on television (five specified the TV *news*). Other information sources which were identified by participants as providing them with the news of the 2009 swine flu pandemic included: radio, family friend, newspaper, schoolteacher, magazine and a poster in the Emergency Department of the local hospital.

Question 3

No participants recalled having contracted the 2009 swine flu or having known anyone who did. For one interviewee this observation appeared to be associated with the belief that swine flu was not very prevalent at the time, (which was not the case, even though case fatalities were low compared with seasonal influenza), *"No I didn't catch it. And no one I can think of I know caught it either. It was pretty rare wasn't it? Yeah pretty rare"* (Martin). Regarding *perceived likelihood* of themselves contracting swine flu in 2009, none of the interviewees thought it was likely, and none was significantly *worried* that they would "catch it". At most, were comments such as "*a little bit*

worried that I could catch it but not too much" (Angus) and "s*ome chance I could get it, but not that much*" (Alan). None of the participants remembers changing his / her day-to-day life as a result of hearing about the prevailing swine flu pandemic. A typical response was " it didn't affect me at all" (Hugh).

In terms of risk perception for seasonal influenza, the majority of interviewees reflected that they would be unlikely to contract it and that it would not be serious for them if they did. Many of these patients attributed their view to specific health behaviours that have a protective effect e.g. "*Not very likely because I have the Fluvax every year*" (Ronda). However, four participants conveyed that their chances of contracting seasonal influenza were significant. Three of these appeared to base their self-assessment on previous experience.

Alan

"I seem to get it most seasons"

Nigel

"I tend to get one flu a year"

However, one interviewee's risk perception of likelihood to contract the flu appeared to more affected by a single atypical recent experience rather than the long-standing pattern for him.

Angus
"Probably could get it quite easily. But I'm not worried about it too much. I'd get over it. I almost never get the flu. Did this winter but. "

In responding to the question on likelihood of contracting seasonal flu, two participants made a comparison with others.

David
"Probably a little less likely to catch it than other people. And umm, yeah, I don't think it would be too serious for me if I did catch it"

Interviewer
"Can I ask you why you think you would be less likely than others to catch it and also why you don't think it would be serious for you if you did contract it?"

David
"Because I eat healthily, and try to keep pretty healthy. And Echinacea would give me some protection even if I did come down with it"

It seems possible that these responses reflect an element of optimistic bias, discussed in chapter two. As Weinstein (1984) pointed out, people may not consider the possibility than others may be taking the same protective actions as they are. On the contrary, another candidate articulated her protective behaviours but rated her chances as the same as others.

Samantha
"The probability of me getting it is average. I wash my hands after the toilet. I don't use paper towels. I don't touch stair rails when I go down stairs."

Only one candidate expressed the view that it could be serious for her if she contracted seasonal flu.

Samantha

"If I did get it, it could make me pretty sick, though. The cough can go on for over a month"

Question 4

Somewhat surprisingly, only one participant reported having been spoken to face-to-face about hand washing, wearing a mask or social isolation / distancing. This conversation was with the nurse at the general practice that he attends. Another participant remembers hearing about these protective measures through a "training video" at the supermarket where he was working.

Generally, participants were supportive of hand washing, social isolation / distancing, and vaccination as protective measures against influenza, whereas only one participant clearly saw wearing a face mask as feasible. All participants bar one expressed a willingness to have a vaccination for seasonal flu, and the one who did not, believed it would be a useful measure for a certain occupational group, "people doing the garbage" (Marnie).

Other items seen by participants as providing some degree of protection against influenza included: vitamins; horseradish and garlic; garlic (alone); spraying surfaces with disinfectant; changing bed clothes regularly; having one's own exclusive drink bottle which no one else uses; washing clothes; eating well, including "plenty of vegetables"; and generally "taking care" of oneself.

Question 5

All participants except one had heard about bird flu. Mostly this awareness was through watching television. However, two interviewees had heard about it from their GP. Nine participants did not worry about a future pandemic, like avian influenza, coming to Australia and saw their own likelihood of contracting it as low. Of the remaining two interviewees, one communicated that he was uncertain about his risk and indicated he would need to seek more information at the time to assess risk.

David
"*Umm, yes I've heard about bird flu. It started somewhere in Asia didn't it? But I really don't know much about it. With future pandemics I guess I'd just keep my eyes open and deal with it on a case-by-case basis. See what information comes through on the official website - how serious it is, how quickly it is spreading, what I should do*"

The other interviewee communicated that she would be worried if bird flu reached Australia, believing that she might catch it, and that it could be serious for her if she did.

Ronda
"*Bird flu. I've heard of it. On the TV news and on the radio too. Yeah..I would be worried if it came to Australia. I would be worried that I could catch it. I've heard that it is very serious. Ten times worse than normal flu. So it could be serious for me if I caught it......*"

Although most participants saw their own likelihood of contracting bird flu as low, only two of these (in addition to the participant above) viewed it as a *potentially* serious situation for them if they did catch it and appeared more

cautious in their comments about seriousness, including how they would deal

with it.

David
"Would talk to my GP if it came to Australia and a lot of people were getting sick"

Tina
"..hopefully there would be an antibiotic against it or a flu vaccine. If it was thought to be serious I would take antibiotics or have the vaccination"

Question 6

In response to being asked what information about influenza in general they

thought was important for people to know, a frequent response was *knowledge*

of how to protect against it (discussed further in thematic analysis).

Amy
"What to do if you get it and how to prevent it"

Angus
...*"the best way to protect against it and should you have a vaccination or not"*

Tina
"Ummm...Well, how to prevent coming into contact with it. Also what medications are available for it..."

Nigel
"Wash your hands and keep away from people with it"

Other information participants thought would be important to know included how "strong" the circulating virus was, and what symptoms characterized the influenza illness (again, these issues will be expanded on in the following section on thematic analysis).

6.8.2 Thematic analysis

Findings are presented within each of the following themes (and its sub-themes): (1) contracting influenza, (2) protecting against influenza, (3) knowledge about influenza, and (4) involvement of general practitioner.

(1) Contracting influenza

This theme captures participants' views, attitudes and experiences related to "catching" an influenza infection, and includes sub-themes of diagnostic uncertainty, the "illness experience", self-management (including rest and over-the counter [OTC] medication), and minimizing spread to others. It includes elements of both seasonal and pandemic influenza.

Diagnostic uncertainty

Participants were aware that, at least in the initial phases, other conditions, such as "a cold", can mimic the symptoms of influenza, and produce diagnostic uncertainty.

David [when asked if he had ever had the flu]
"I'm not really sure. [Slightly quizzical facial expression] *I've had symptoms sometimes that seemed like the flu but I'm not sure that it was actually flu".*

It is not possible to be certain that symptoms consistent with a clinical diagnosis of influenza are in fact due to an influenza infection, without confirmation through laboratory tests (e.g. serology or polymerase chain reaction). In this sense, David's response reflects a sophisticated perspective. However, in routine clinical practice such laboratory confirmation is generally viewed by clinicians and health authorities as unnecessary, with added cost to the patient or community, without altering management. Therefore, there is value in knowing what symptoms are consistent with an influenza illness. Reflecting this was a view among participants that it is useful to be able to distinguish between a "cold", which is mostly mild and transient, and influenza, which can have serious complications.

Ronda [when asked about important information for people to know]
"Umm...How do you tell the difference between a cold and the flu?"

Interviewer
"Why do you think that is important?"

Ronda
"Because a cold is not serious but the flu can be."

Some participants expressed their thoughts on how to differentiate between the two.

Samantha
"How can you pick a cold from the flu. That's important. Flu lasts a lot longer and you are sicker. The cough can last for five and a half weeks."

Amy
"I don't think I've ever had a flu. I've had colds but the flu is worse isn't it? People almost feel like they're dying don't they when they get the flu?"

Knowing the symptoms of the specific circulating influenza infection was identified by many participants as important knowledge for people to have.

Hugh [when asked what information about influenza is important]
"Ummm...the symptoms to watch out for. And what treatments are available."

Linked to this theme is the finding, in the 2009 survey, of a poorer knowledge of influenza in people with schizophrenia compared with those attending a general practice (only 14% of participants in the SCZ group were able to name three symptoms of influenza compared with 32.5% in the GP group). As identified by interviewees in this qualitative study there is practical value in the public having knowledge of the symptom profile characterizing a prevailing influenza. It enables people to gauge whether they may have become infected and to seek appropriate assessment and treatment. This is particularly true in the case of a hypervirulent outbreak.

Illness experience

Despite *some* participants finding similarity in symptoms of "colds" and influenza, the "illness experience" of having influenza for *many* participants was one of feeling very sick and incapacitated, even moribund.

Martin
"Yeah..I'd reckon I've had about 4-5 episodes. Two really bad ones. Yeah when I thought I was dying."

"Felt too sick to get out of bed"

Samantha
"Once, in 1999. I was bed-ridden... [Shakes head slightly] *I had no energy at all, had to drag myself around."*

Hugh
"Yes, once, when I was 15. I was pretty sick with it - vomiting [Frowns] *and needed antibiotics."*

For one participant, the illness experience was so vivid, she still remembered how she felt after over two decades.

Marnie
".....Twenty-two years ago when my son was two. I remember sweating so much and feeling terrible [Frowns]*. I think I had the flu."*

Self-Management and *reducing transmission to others*

These two subthemes are discussed together because they share some coded extracts. Participants highlighted the importance of rest during an influenza illness, which is consistent with an illness experience of being "bed-ridden" (as above).

Samantha

"Rest. Rest is important - if you've got the flu you should rest for a few hours during the day as well as at night. Oh, and you should take time off work to rest and to not spread the flu to everyone else."

Martin

"Take time off to recover. Don't push yourself until you are well again. Yeah... generally take life easier. Ay."

As identified by Samantha above, an additional gain to the intrinsic benefits from rest for the influenza sufferer him/herself, is that if some one is resting at home, they are *less likely to be spreading* the virus to others in the community (with the exception of co-residents).

While most participants didn't mention a role for OTC medication, several did advocate its usefulness. One participant mentioned treating a "dripping nose" in the context of *reducing the spread* of influenza, as well as for symptomatic relief.

Interviewer

"....Now, can I ask you what are your thoughts generally on things you can do to try to avoid catching influenza?"

Samantha

.......You should also medicate against a dripping nose. You can use a decongestant and antihistamine."

Interviewer

"Why do you think it is important to stop a dripping nose?"

Samantha

"Helps stop the virus spreading. You feel better too."

However, the role of OTC medication was also viewed solely as symptomatic treatment until the flu passed.

Martin [when asked about risk perception of seasonal influenza]
"Yeah... I've been getting it every year for the last few years. It's not too serious because I take Codral Cold and Flu tablets and stay in bed for 2-3 hours during the day."

Interviewer
"Can you describe to me how these help?"

Martin
"Ummm...make you feel better till you get over it. Ay."

Although the specific questions asked in the topic guide framework related to ways of avoiding contracting influenza *oneself*, several participants, revealing a community consciousness, also viewed this through the prism of reducing viral transmission to others.

David
"But I'd definitely stay at home if I caught a bad flu. People at work don't appreciate it if you give the virus to them. That's not responsible [Stated emphatically]. *And the flu will last longer if you go to work instead of resting at home."*

Samantha
".... Oh, and you should take time off work to rest and to not spread the flu to everyone else."

(2) Protecting against influenza

This theme captures participants' views, attitudes and experiences related to preventative measures and other factors associated with a reduced risk of

contracting an influenza infection. Its sub-themes include avoiding exposure to the flu virus, a prominent role for hand washing, the importance of good general physical health, alternative medicine, nutritional supplements, and specific groups. It contains elements of both seasonal and pandemic influenza.

Avoiding exposure to the flu virus

Participants perceived the benefits of taking steps to avoid *exposure* to the influenza virus in order to prevent contracting the infection. This included both social distancing as well as precautions against coming into contact with objects or surfaces that the virus may be situated on. In terms of social distancing to protect against a future pandemic influenza, some participants emphasized the importance of avoiding airports and contact with those who have travelled recently.

> **Samantha**
> *"... I probably wouldn't catch it because I don't go to airports where these viruses come in."*
>
> *"I wasn't overly worried. I was not going on any overseas travel or mixing with people who had been travelling."*

Others just stated emphatically that one should avoid proximity to anyone infected with influenza.

> **Nigel** [when asked about what information about influenza is important for people to know]
> *"Wash your hands and keep away from people with it"* [Stated confidently].

It was perceived as an important protective strategy by some participants to avoid direct contact with surfaces or objects potentially contaminated with the virus, or to neutralize the virus on these surfaces.

Alan
"Yeah, umm... spraying surfaces with Glen 20."

Martin
"Changing my bedclothes regularly. Um ...oh yeah, and having a drinking bottle that only I use. No one else uses" [Facial expression of determination].

Samantha
"....I don't use paper towels. I don't touch stair rails when I go down stairs."

Amy
"I catch the bus so maybe it is more likely for me to catch flus. But mum gives me anti-stress hand wash, and I think this helps. And I try not to touch anything on the bus" [Pause].

These strategies are very feasible given that current scientific thought is that influenza viruses can remain on hard surfaces for up to two days (Australian Government, Department of Health. Influenza, Protecting yourself and others 2012). It was important to obtain this aspect of how people with schizophrenia think about influenza, as it was not a Likert response option in the 2009 cross-sectional survey, and yet it is an effective protective measure.

Another aspect of *avoiding contact with virus* identified by participants relates to sneeze / cough etiquette. Again, this was not a response option in the Likert-

type items in the thesis survey, and was mentioned spontaneously during interviews.

David [during response to question about hand washing, wearing a mask and keeping away from others]
"Umm...and covering your nose when sneezing" [Places right hand near nose]

Samantha [when asked what information about influenza is important for people to know]
"......Also not to cough in front of people"

These responses again reflect a community-mindedness rather than solely one's own personal perspective.

A prominent role for hand washing

Despite all bar one participants communicating that they had not been spoken to face-to-face about hand washing as a protective action against contracting influenza, it received a strong endorsement from participants in the in-depth interviews. This response was congruent with findings in the thesis survey. The prominent role for this preventative measure in people's view was evidenced by it being spontaneously mentioned in many different segments of the interviews, not just in reply to the specific question item on how to avoid catching influenza. When asked what he viewed as important information people should know about influenza, a participant cited hand washing as his opening comment.

Nigel
"Wash your hands and keep away from people with it" [Stated confidently].

Samantha [in response to question about important information about influenza for people to know]
"That it can be passed from human to human by droplets. Hence the need to regularly wash your hands."

Amy [when asked about hand washing, wearing a face mask and social distancing / isolation)
".....I know that keeping hygienic is the best way. .....Staying hygienic is very important. I always try to keep my hands clean."

One participant believed so strongly in the importance of hand washing that she disclosed that she would not permit entry into her house by people she thought did not practice it.

Marnie
"Also I won't let anyone into my house who has dogs. They carry a lot of germs. Their owners don't wash their hands properly [Looks slightly annoyed]. *It's true."*

It was recognized that hand washing does not necessarily require running water, due to the existence of containers of hand washing liquids.

David
".....when I go to have blood taken for clozapine I see those dispenser things containing disinfectant. These are good 'cause you don't need a sink or running water."

Amy
"I catch the bus so maybe it is more likely for me to catch flus. But mum gives me anti-stress hand wash, and I think this helps"

This awareness of liquid hand washes is significant because one of the principal barriers to increased hand washing cited in the 2009 survey was lack

of washing facilities, such as basins and sinks. In addition, as discussed in chapter two, hand washing with alcohol-based gels has been shown to be a highly effective protective measure against respiratory viruses.

In contrast to the perceived effectiveness and convenience of hand washing as a protective measure, there was very little support for wearing a face mask, with reasons offered spontaneously for their rejection. This finding was consistent with the majority of responses in the 2009 thesis survey.

David
"I probably wouldn't want to wear a face mask. I don't think they do much good, do they?"

Alan
"Because my GP never told me I should. Also I don't think the nurse said I should wear a mask either"

Marnie
"I don't like masks, you can't breathe properly with them, but they can stop you breathing in dirt"

General health factors

Although there was no mention by any participants of smoking, alcohol misuse or obesity as risk factors for contracting influenza and developing its complications, several participants identified the importance of a healthy lifestyle and good general physical health, as protective factors.

Interviewer
"Can I ask you why you think you would be less likely than others to catch it and also why you don't think it would be serious for you if you did contract it?"

David
"Because I eat healthily, and try to keep pretty healthy....."

"Diet is important. Eating plenty of vegetables.."

Martin
"Diet and exercise are important. Veges too."

In one instance, an important role for the immune system was cited.

Ronda
"If you didn't do these sort of things [hand washing, wearing a face mask and keeping away from others with the flu] *and got the flu, then you were going to get it anyway, and it wouldn't have helped you even if you had done those things. It's your immune system that matters."*

Alternative medicines and *nutritional supplements*

Another significant theme identified from the in-depth interviews that was not elicited in the thesis survey was the value attached to alternative (i.e. 'complementary') medicines. As mentioned earlier, ginger tea and Echinacea were cited as treatments for an influenza illness, whereas for prophylaxis against catching influenza in the first place, garlic and horseradish, and garlic alone, were nominated. Interestingly, participants who expressed a belief in taking alternative medicine also took nutritional supplements, vitamins or fish oil tablets.

Nigel
"Well, like I said before, I have the vaccine every year. I also take Bio C tablets and garlic tablets if there if a flu going around to ward it off."

Interviewer

"Right. OK. And Amy, what are your thoughts generally on things you can do to try to avoid catching it?"

Amy

"I take horse radish and garlic. Oh, and fish oil tablets as well."

Interviewer

"Now, can I ask you what are your thoughts generally on things you can do to try to avoid catching influenza?"

Samantha

"Multivitamins. I take multivitamins. And garlic and horseradish. You should also medicate against a dripping nose. You can use a decongestant and anti-histamine."

Significantly, these data extracts also indicate that a belief in, and the taking of, alternative medicines and vitamin/nutritional supplements, was not mutually exclusive with beliefs in more traditional measures, such as flu vaccinations and orthodox symptomatic medication (e.g. antihistamines). Nor was it associated with a rejection of, or non-engagement with, a general practitioner. Indeed, there are general practitioners who have a special interest in complementary medicines, who may be sought out by patients with similar views. However, the CDC is very clear on their recommendations regarding alternative medicines, asserting, "There is no scientific evidence that any herbal, homeopathic or other folk remedies have any benefit against influenza." (Centers for Disease Control and Prevention. Preventing Seasonal Flu Illness 2013).

Specific groups

Although potentially in a vulnerable group themselves (as people with schizophrenia), several participants identified specific groups that may require special attention and assistance in the context of serious influenza outbreaks. These included the very young, older adults and, as mentioned in the framework approach, people who may be at risk because of their occupation.

Alan
"Pay attention to babies and very young people when there is a bad flu going around."

Samantha
"It is important for the policy to ask people over 65 if they have had a vaccination."

Interviewer
"How do you feel about having a vaccination to protect against the flu, especially it were one of those big flus, a pandemic flu, we spoke about earlier?"

Marnie
"I don't believe in them for myself. But people doing the garbage need to be immunized."

The participant felt so strongly about the extra needs of this occupational group that she repeated her concern later in the interview, with a facial expression congruent with the intensity of her belief.

Marnie
"People doing the garbage need to be told they should be immunized" [Look of determination on face].

However, despite recognizing the special needs related to the demographic of age, no participants articulated the protective needs of other established higher risk groups, such as Indigenous people and pregnant women. The reasons for this are not clear from this study, but may include a simple lack of awareness.

It is relevant to compare participants' views regarding how they can protect against influenza, with the recommendations of the CDC. These are listed in Table 6.3. Collectively, participants in the present qualitative study nominated all of the CDC's recommendations, except the final two. This suggests that their access and utilization of information sources for what many saw as the most important information to know about a flu i.e. "how to protect against it", was at least reasonable.

Table 6.3 Recommendations for seasonal influenza prevention by CDC

1. The single best way to protect against the flu is to get a flu vaccine each year. CDC recommends that everyone 6 months and older, especially people at high risk for developing serious complications from flu, get vaccinated each season 2. Try to avoid close contact with sick people. 3. If you are sick with flu–like illness, CDC recommends that you stay home for at least 24 hours after your fever is gone except to get medical care or for other necessities. Your fever should be gone without the use of a fever-reducing medicine. 4. While sick, limit contact with others as much as possible to keep from infecting them. 5. Cover your nose and mouth with a tissue when you cough or sneeze. Throw the tissue in the trash after you use it. 6. Wash your hands often with soap and water. If soap and water are not available, use an alcohol-based hand rub. 7. Avoid touching your eyes, nose and mouth. Germs spread this way. 8. Antiviral medications, which can treat flu illness, may be used in certain circumstances to prevent the flu.

Knowledge about influenza is a core theme in the qualitative study. It influences the theme *protecting against influenza* and is influenced by the theme *involvement of GP.* It encompasses both general knowledge about influenza as well as knowing relevant information about a specific circulating influenza outbreak. Sub-themes include trust in information sources, media and public messaging, family and friends, and seriousness of viral strain.

Trust in information source

In contrast to the 2009 survey, there was no question in the interview topic guide specifically enquiring about *trust* in the in-depth interviews. In this sense, and also because an NVivo "Text Search" revealed that the word "trust" appeared only once in the entire data set, trust is a *latent* (rather than a *semantic*) sub-theme.

A participant revealed his sense of trust in official Internet websites (established during a serious influenza outbreak) by reflecting on what he believed would be their positive attributes - being both up-to-date and accurate.

> **David**
> *"If I heard that there was a really serious flu going around, and I wanted to get information about it, I would go to an official website* [Confident facial expression]........*"*
>
> **Interviewer**
> "All right. Can I ask you why you would choose this as an information source?"

David

"Yes, because they would know the latest information. And they would know what they are talking about [Stated emphatically]......

Trust in an information source is a particularly important theme because, as discussed in Chapter two, levels of trust are predictors of health behaviours. Indeed, later in the interview the same participant indicated that he would be *willing* to have a vaccination if the official website reported the circulating viral as "serious" and recommended it.

David

"Yeah... if it was a serious flu I would be willing to be vaccinated, if one was available. But not for a weak flu, like swine flu was. It wouldn't be worth it."

Interviewer

"How would you know whether a new flu was a serious one of not, and whether it would be worthwhile having a vaccination, if one were available."

David

"As I was saying before, I'd check on the official website........"

Similarly, there is implied trust in a professional family member, underpinning the comments in the following extract.

Interviewer

"If you wanted to find out more about a flu that was "going around" or about influenza in general, how would you go about this?"

Tina

"Ask a doctor. Or my brother. He is a microbiologist."

Interviewer
"Hmmm......that sounds helpful, to have a person in the family with that kind of knowledge and training."

Tina
"Yes it is."

In contrast, some participants expressed a sense of distrust, and even outright scepticism, regarding the media's reporting of information about influenza outbreaks, articulating a view that the media exaggerate issues. There appeared to be a particular emphasis on *television* in this respect.

David [with reference to swine flu]
"No, I didn't think I would be likely to get it. And I think it was blown out of proportion by the media. In the beginning they were saying on TV that it was really serious but later I heard on TV that it was not even as bad as normal flu."

Angus
"Bird flu. Yes, heard about it on TV. Sounds serious but I'd be worried that they were bunging it on. You know, just making a story out of it."

Ronda
"Bird flu. I've heard of it. On the TV news and on the radio too. Yeah...I would be worried if it came to Australia. I would be worried that I could catch it. I've heard that it is very serious. Ten times worse than normal flu. So it could be serious for me if I caught it but it's hard to know because the media always exaggerates things."

Media and public messaging

With respect to the different forms of media, television was easily the most frequently mentioned across the entire data set. An NVivo "text search"

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revealed that the term "TV" appeared twenty times. Most of these related to how participants had heard about swine flu or bird flu, but there were two others contexts. The first related to public messaging about influenza.

Interviewer
"OK. Amy, is there anything else about influenza you feel is important or that you would like to tell me that I haven't asked about?"

Amy
"Make information available to the general public. TV ads...

Given that so many participants reported learning of the emergence of the 2009 swine flu, and also of the existence of bird flu, through watching television, it would appear that community messaging about important aspects of influenza through this medium is a worthwhile government initiative. In addition, the 2009 survey revealed that television was a common information source for obtaining health information in general, not specifically relating to influenza.

The second context was that television was specifically identified as an information source that would be actively used to seek out more information about a circulating influenza virus or about influenza in general.

Marnie
"I'd watch the TV - they have a special section on flus as part of the news...."

In contrast, radio was mentioned only three times over the entire data set. Two of these related to hearing about swine flu (from the one participant) and one to learning about bird flu (from a different participant). Interestingly, both of these participants had heard about these influenzas through other forms of media in addition to radio.

Newspaper was mentioned by only two participants (both relating to how they heard about swine flu) and magazines by only one participant (again in the context of how she learned about swine flu). Interestingly, the terms "Internet", "Twitter", "Facebook", "smart phone", "mobile phone" or "tablet" (or commercial equivalents) did not appear at all in the data set, resonating with the findings in the 2009 survey that people with schizophrenia were less likely than the general population to access the Internet to obtain health information. Given the increasing utilization of online services and information in health delivery, further exploration and expansion of the role of e-health for people with schizophrenia is required.

Participants saw a role for posters and written information in public messaging about influenza.

Amy
"The RTA [Road Traffic Authority] *should put it on bus timetables and on public transport. Also have it at Centrelink and Government places...."*

Nigel
"Umm....I don't mean face to face, I mean you see this sort of stuff on posters around the place. Like at the doctors."

David
"And perhaps the government could produce a fact sheet and put this up in places like GP surgeries or public places."

Family and friends

Over a third of participants identified family or friends as potential sources of information on influenza. This was both in the context of seeking information about a circulating influenza, and general information on influenza. For two participants the family member or friend had special knowledge about influenza, by virtue of their work.

Tina [in context of seeking more information about influenza]
"Ask a doctor. Or my brother. He is a microbiologist."

David [in context of seeking more information about influenza]
"Also I have a family friend who works in that area, who I could ask about influenza."

Martin [in context of seeking more information about influenza]
"I'd talk to someone in my family about it. Yeah, I reckon that's what I'd do."

Ronda [in context of seeking more information about influenza]
"Umm.... I'd ring Health First or talk to some one in my family, or talk to a friend."

Although family or friends were nominated as information sources, this was not at the exclusion of seeking guidance from a general practitioner, who was also identified as a chosen information source.

Seriousness of viral strain

Generally, it appeared important to participants to know how virulent the circulating influenza virus is, especially in terms of guiding what actions to take in the circumstances.

David
"With future pandemics I guess I'd just keep my eyes open and deal with it on a case-by-case basis. See what information comes through on the official website - how serious it is, how quickly it is spreading, what I should do."

Interviewer
....what information about flus in general do you think it is important for people to know?

Angus
"The main things would be....[Pause] *how serious the strain is, the best way to protect against it and should you have a vaccination or not."*

One participant even conceptualized a possible 'seriousness level' of *fatal outcome*, which she believed people should be informed about.

Interviewer
"......what information about flus in general do you think it is important for people to know?"

Tina
"Umm...Well, how to prevent coming into contact with it. Also what medications are available for it. And whether it is terminal as a disease."

<u>(4) Involvement of GP</u>

The final theme interacts with all of the previous themes and captures how participants view, access and interact with their GP. Its subthemes include physical check-up, vaccination, and trust in GP.

Physical check-up

Although participants predominantly viewed influenza as an illness that requires rest and that will resolve spontaneously, many articulated that a physical check-up by their GP was an important aspect of the way they dealt with the experience of having influenza. There was even the implication that it assisted in the recovery process.

> **Interviewer**
> "Did you see a doctor at that time and if you did, did you find this helpful?"
>
> **Marnie**
> *"Yes, used to go to a GP called Dr K-   I saw him and got better."*
>
> **Interviewer**
> "Do you think he helped you to get better?"
>
> **Marnie**
> *"Yes. He did a physical checkup."*

Comments also reflected an underlying awareness that influenza can have complications, which may seriously threaten one's well-being.

> **Alan**
> *"Yes, I see my GP when I get the flu."*

Interviewer
"Do you find that helpful?"

Alan
"Yes."

Interviewer
"In what ways?"

Alan
"Well, I get a checkup to make sure I am OK."

There was an appreciation that information given by a doctor on a circulating influenza, especially on what to do if infected, may depend on what the physical examination findings are. For instance, whether antibiotic medication is recommended or not, is largely determined by findings on examination of the respiratory system. Absence of physical signs of a bacterial infection may result in information about rest being the main treatment, an approach that appeared to be accepted by participants.

Interviewer
"Did you try to find out more information about the flu on these occasions?"

Ronda
"No, I didn't need to. My GP checked me and told me what I should do. Mainly just rest and take it easy."

Vaccination and *trust in GP*

These two sub-themes are discussed together because, although they are distinct categories, they are interrelated. A decision whether or not to have a

vaccination was often viewed as being dependent on how virulence of the causative viral strain.

David
"Yeah... if it was a serious flu I would be willing to be vaccinated, if one was available. But not for a weak flu, like swine flu was. It wouldn't be worth it."

For many, but not all, participants, this important decision appeared to be guided by *trust* placed in the knowledge and judgement of the GP (although, as indicated earlier, the actual word "trust" was used just once in the entire data set).

Martin
"Normally, I'm not that keen on needles, but I would trust my GP. If he reckoned I should get it I probably would."

Angus [with respect to receiving a vaccination against influenza]
"I'd be willing to have one if my GP told me to get it."

However, there was evidence that a helpful trusting professional relationship with a GP was not ubiquitous.

Interviewer
"OK. Would you consider any other information sources?"

Hugh
"No, not that I can think of."

Interviewer
"Would you consider talking with your GP?"

Hugh
"Ummm [Wry smile]*......I don't really see a GP that much."*

However, in general, the content, tone and nature of language used when describing GP involvement was respectful and appreciative. It seems likely from comments made in these interviews that for many participants an active and core role will be played by the general practitioners in the event of a future pandemic.

6.10 Review of research questions

A summary of the findings of the qualitative study is presented within the context of the research questions.

(1) What is the illness experience of influenza for people with schizophrenia?

There was a large range in the illness experience of influenza both in terms of frequency of episodes and the subjective experience of severity. While one participant did not recollect ever having experienced influenza, and many only once in their lives, others disclosed that they contracted it yearly. For some the illness experience was mild, finding the symptoms similar to those of a "cold". Others felt incapacitated, were vomiting or sweating, had extreme lethargy, and even thought they were dying. Part of the illness experience is reflected by what people viewed as ways of mitigating the negative impact of contracted influenza. Rest was generally seen as important, including taking time off work.

Other measures included alternative medicines such as Echinacea and ginger tea, and more traditional over-the-counter medication such as decongestants and antihistamines. In addition to providing symptomatic relief, the latter were also viewed as helpful in reducing spread to others in the community (by reducing nasal discharge). Furthermore, there was an awareness of other measures to assist with this endeavor of reduced viral transmission during an influenza illness, such as sneeze (and implied) cough etiquette. Finally, it was viewed as important to seek a physical check-up from a GP to exclude complication of the illness.

(2) How do people with schizophrenia seek information about influenza?

Participants revealed that they actively sought information about influenza from a variety of sources. The majority cited speaking with their GP to obtain information about both a prevailing influenza as well as influenza in general, and appeared to invest trust in their GP as an information source. Other identified sources which participants reported accessing included: television; medical journal (in a library); the Internet (only one participant, who indicated use of online services and his trust in the accuracy and up-to-dateness of an official website); work staff; family and/or friends; psychiatrist; and a government 'walk-in centre'. Radio and newspaper were not used to actively seek information about influenza. Several participants expressed a sense of distrust in the media, especially television, due to a perceived tendency towards exaggeration and hyperbole. They indicated that this might affect how they perceived the risk of an influenza outbreak.

(3) How did people with schizophrenia become aware of the swine influenza pandemic and what is their recollection of their risk perception of it?

All participants bar one remembered hearing about the swine influenza pandemic during 2009. There was a range of information sources that provided awareness of this outbreak. The most frequently cited was television (especially the *news*) but others included radio, newspaper, magazine, family and friends, school teacher, and a poster in the Emergency Department of a hospital. Generally, there was a recollection of low risk perception, especially low *perceived likelihood of contracting it*, and low levels of *concern* associated with awareness of this pandemic.

(4) How do people with schizophrenia view protective measures against influenza

The key finding here was a strong endorsement of hand washing and vaccination, for both seasonal and pandemic influenza. Willingness to receive a vaccination was often linked to virulence of the prevailing viral strain and trust in the GP's decision of whether it was required or not. On the other hand some participants routinely have a yearly vaccination to protect against (seasonal) influenza. In addition to hand washing and vaccination, other protective strategies included: avoiding exposure to the virus; taking oral supplements (vitamins and/or fish oil tablets); taking alternative medicines (horse radish and garlic, garlic [alone]), washing clothes and bed linen regularly, and healthy lifestyle factors (eating well, including abundant

vegetable intake, and exercise). In terms of avoiding exposure to the influenza virus, specific measures identified included: spraying surfaces with disinfectant; not touching stair rails; not sharing drink bottles with others; and distancing from airports and people who have recently travelled overseas (during an influenza pandemic).

(5) *How do people with schizophrenia perceive the threat of a future pandemic influenza, including bird flu?*

There was generally a low risk perception, and low level of concern, regarding a future influenza pandemic, including the possibility of bird flu (which all participants bar one had heard of). The very large majority of participants perceived their own *likelihood* of contracting the viral infection as low, and only two viewed it as potentially *serious*. There was a belief by one of these that there may be an antibiotic (or vaccination) for the future pandemic, which she expressed a willingness to have if the viral strain were "serious". There was an awareness by one participant that the risk associated with a future pandemic may not be known until the time of its occurrence and that a reasonable strategy would be to monitor information provided by official websites, in terms of its threat potential such as "seriousness" of viral strain and rate of transmission. It seems *possible* that there may be an element of complacency regarding perceived risk from bird flu or other highly pathological viral strains, related to the low virulence of the recent swine influenza pandemic.

(6) What information about influenza do people with schizophrenia believe is important for the public to know?

There were several key items of information about influenza that participants identified as important for people to know. However, foremost among these appeared to be information on how to protect against the infection. Participants saw a need for information on the virulence of the particular viral strain and the associated decision whether nor not to have a vaccination. They also believed the public should know about importance of hand washing in protecting against the spread of infection. Participants indicated that they thought it would be helpful for people to be provided with information on the *symptom profile* characterizing the influenza illness, in order to distinguish from other less serious infections such as a "cold", which may mimic it, at least in the early stages of the clinical course. Participants expressed views on how this information could be delivered. They advocated public messaging through the television and posters and other written material, in public places such as bus stops, railways and other public transport, government social welfare offices, and doctors' surgeries. With respect to television, participants added the caveat of the need to be aware of a tendency to exaggerate and distort information.

6.10 Practical implications

There are several critical public health and clinical implications that arise from this study, including:

(1) Public health policies which support and provide encouragement for people with schizophrenia to establish and maintain strong links with a GP, including for provision of information on influenza, advice on whether vaccination is required, and the provision of a physical check-up when necessary.

(2) Ongoing education and provision of information on influenza, including typical symptoms profiles characterizing influenza infections, as well as protective measures. Although often a sensitive area, education should also be provided on which protective measures have an evidence base and which do not.

(3) Television and posters in public places and doctors' surgeries may be helpful conduits of public messages

(4) Further exploration and expansion of the Internet as a possible health information delivery resource, for people with schizophrenia, so that they do not fall behind the general public and become (further) disadvantaged in this respect.

6.11 Strengths and limitations

Limitations

There are several limitations to this study. First, the results cannot be generalized to all people with schizophrenia. Although diversity was aimed for

in the selection of participants these eleven patients represent only a small portion of the spectrum of patients with this mental illness. Second, due to the decision not to audio-record the interviews, it is possible there were small verbal details missed in the hand written notes (although the candidate is confident that if this occurred it was very minimal). Third, it is possible that the researcher's presence during data collection may have influenced participants' responses. For instance, the largely positive remarks about GPs may have possibly reflected a certain level of acquiescence bias in the context of the interviews being conducted by a medical practitioner. However, the candidate tried to neutralize the emergence of this bias by emphasizing to participants at the beginning of the interviews that candid responses were sought and that it was not important what the interviewer's own views might be.

Strengths

Despite the limitations there are also many strengths to this study. First, there is detail and richness in the data, especially when patients describe their personal experiences as well as perspectives that relate to these experiences. Information about what people think and feel about influenza was elicited which had not emerged from data in the cross-sectional study. A relaxed, conversational interview style allowed for clarification of participants' comments with follow-up questions, to ensure that their views and perspectives were being correctly elicited and understood. In addition, affective elements of communication such as observed tone of voice and facial

expression gave added texture and understanding to views and feelings expressed.

6.12 Conclusion

In terms of research aims, the qualitative study has resulted in an increase and enrichment in the understanding of how people with schizophrenia experience and view influenza. Despite being largely consistent with findings in the 2009 survey, the qualitative data obtained from the in-depth interviews revealed additional insights, which may prove useful in protecting people with schizophrenia (and others) during seasonal and pandemic influenza outbreaks. The results suggest a *possible complacency* about future, potentially highly lethal pandemics such as bird flu, perhaps influenced by the low virulence of the recent swine influenza pandemic.

CHAPTER SEVEN

OVERVIEW AND FINAL CONCLUSIONS

7.1 Introduction

This chapter provides an overview of the thesis research project and final conclusions. The overview includes a summary with key findings, a review of the hypotheses, strengths and limitations, practical implications, broader issues and implications, and future research.

7.2 Summary of study including key findings

Background

Although in the past people with schizophrenia were often 'hidden' from society and incarcerated in asylums, most individuals with schizophrenia now live relatively 'normalized' lives in the community. Modern treatments and rehabilitation have assisted most people with schizophrenia to live relatively independently, with equitable rights to timely, high quality and comprehensive medical care and preventative health measures, as required. People with schizophrenia often face significant health threats arising from their vulnerability to comorbid medical disorders, in addition to the risks and challenges associated with their mental illness. One of these health threats relates to influenza, especially in the event of a pandemic, with estimates of up to 7.4 million deaths in the general population globally if an outbreak with a

hypervirulent viral strain occurred. Of particular concern is a future mutation in the highly pathogenic strain of avian influenza H5N1 (which currently has a human mortality rate of 59%) rendering it capable of human-to-human transmission.

Record linkage studies have demonstrated that people using mental health services have a significantly increased risk of hospitalization, and of mortality, from influenza and pneumonia, compared with the general population. These studies have also revealed an excess risk in both need for hospitalization and mortality for men with schizophrenia who contract influenza, and for both men and women with schizophrenia who develop pneumonia. A critical review of the scientific literature revealed a potential vulnerability for people with schizophrenia who contract influenza, significantly heightened in the event of a pandemic, due to: (1) poorer medical outcomes and increased risk of mortality from influenza (and pneumonia), associated with significant medical comorbidity, such as chronic obstructive pulmonary disease, ischaemic heart disease and type II diabetes, all of which occur at higher rates in people with schizophrenia compared with people in the general population, (2) poorer medical outcomes from influenza (and pneumonia), associated with smoking, alcohol misuse and obesity, all of which have an increased prevalence in people with schizophrenia compared with people in the general population, and (3) inequities in health care access and delivery for people with schizophrenia.

Epidemiological modeling suggests that an effective response plan could significantly reduce the number of deaths and hospitalizations associated with an influenza pandemic. A core component of an effective response is the employment of *protective measures*. These are particularly important for vulnerable groups, including people with schizophrenia. Vaccination can reduce the number of people infected in a pandemic, as well as hospitalization and mortality rates. However, inevitable delays occur in the development of an effective vaccine during a pandemic. In addition, there are likely to be limitations in the supply of both vaccines and anti-viral medication. Therefore, other protective measures are also important to control the outbreak. Increased hand washing, social isolation and wearing a surgical face mask, have all been demonstrated to be effective in reducing the spread of respiratory viruses. Their use during a pandemic influenza has been endorsed by the Centres for Disease Control and Prevention for the community containment of viral transmission. Computer modelling has shown that uptake of protective measures even by only a relatively small proportion of people in a community can have a favourable impact on the trajectory of an influenza pandemic. Therefore, it is useful for pandemic influenza preparedness and response planning to gain knowledge about people's willingness to adopt such protective measures, and factors that may influence this willingness.

Protective behaviour is linked to a person's risk perceptions of the health threat as well as their evaluation of the potential benefits and barriers associated with a given preventative action. Risk perception has been shown to influence how

people respond to threats such as an influenza outbreak. Key dimensions of pandemic influenza risk perception include *perceived likelihood* of becoming infected with the respiratory virus, and the *perceived seriousness* if this occurred. Affective factors, such as *feelings* of vulnerability, during a pandemic, can play a role in influencing risk perception. Self-efficacy is also important, as it has been shown to be a predictor of adaptive health behaviours.

How an individual gains i*nformation* about a given health threat, and the level of trust invested in the source of that information, influences risk perception, which, in turn, can influence willingness to adopt protective behaviours. Therefore, another core component of an effective response plan for pandemic influenza is the effective communication of accurate, relevant and up-to-date *information.* This information is needed to notify the public of the emergence and nature of the influenza outbreak and what they need to do about it.

The principal focus in the thesis study has been on pandemic influenza. However, a better understanding of people's willingness to undertake protective measures against influenza during a pandemic is relevant to attempts at reducing the negative health impact of seasonal and sporadic influenza, as well as other outbreaks of serious respiratory infection.

Although the threat of pandemic influenza has worldwide relevance, the focus of the candidate has been on the Australian pandemic experience. The

Australian Health Plan for Pandemic Influenza emphasizes the importance of (1) effective communication of relevant health information to the public during a pandemic influenza, including recommendations about protective measures, and (2) concerted efforts to reduce transmission of the virus. These are also core themes in the focus of global response strategies for pandemic influenza.

Study designs and aims

Therefore, the candidate initiated a cross sectional study supplemented by in-depth interviews, with a multifactorial public health approach, to explore factors that may be amenable to change through improved public health policy, programmes and targeted campaigns. As such the research project was designed to obtain data on how people with schizophrenia: (1) obtain information on health matters, (2) perceive risk associated with pandemic influenza, (3) report their level of willingness to engage in protective measures during an influenza pandemic, associated self-efficacy and how effective they view these protective measures to be, and (4) perceive barriers to carrying out a given preventive measure. There are currently significant gaps in the knowledge base in all these domains with respect to people with schizophrenia. It was hoped by the candidate that the data gathered in this thesis research project, and the associated findings, could be used to improve pandemic influenza preparedness and response planning and to mitigate the negative impact of such an event for this very vulnerable group.

<u>(1) Cross-sectional survey</u>

Sample, recruitment and measures

A naturalistic "real world" setting was sought for this research study resulting in the recruitment of participants from health care settings. A purposive sample of 71 adults (aged 18-65 inclusive) in the Australian Capital Territory diagnosed with schizophrenia by their treating psychiatrist was recruited from health care settings: fifty from community mental health centres; twelve from a psychiatric hospital inpatient unit; and nine from a psychiatric rehabilitation unit. The level of functioning of these patients was sufficient for them to be able to consent to, and participate in, the study. From thirteen predominantly small urban group general practices in the Australian Capital Territory, 238 volunteers who did not report a diagnosis of schizophrenia were recruited for the comparator group. The survey was carried out over a four-month period from July to October 2009, commencing three weeks after the global H1N1 outbreak was declared a pandemic by the WHO on 11 June 2009. All participants completed a questionnaire, which included items on:

(1) *socio-demographic characteristics* including age, gender, highest level of education, employment status, estimated household income, presence of children in the household, and languages other than spoken in the home

(2) *how much information* on health matters they obtained from, as well as the *level of trust* invested in, various sources, including doctor, the Internet, television, radio, magazines, newspapers, and family and friends

(3) *perceived risk* associated with the H1N109 influenza pandemic, including perceived likelihood of self contracting the virus, perceived seriousness of contracting the virus, feelings of personal vulnerability from the pandemic, and perceived consequences of contracting the virus, including death; associated key parameters viewed as having the potential to influence the perception of risk, including factual knowledge of influenza, affective response, knowledge of the experience of suffering from serious influenza, perceived control over contracting the virus, self-rated general health and Kessler 10 scores

(4) *willingness to adopt a given protective action* against the pandemic influenza if advised to by government health authorities, and self-efficacy regarding each protective measures (except for hand washing)

(5) *perceived effectiveness* of each protective measure as well as *perceived barriers* to carrying out a given protective measure; in the case of vaccination participants were also specifically asked about their perceived risk of an adverse reaction and how concerned they were about contracting influenza from the vaccination.

Principal measures used were 5-point Likert scales. Open-ended and binary Yes-No questions, the 10-item Kessler Psychological Distress Scale, and the Single Item General Self-Rated Health Question were also employed.

Key findings

People with schizophrenia most commonly reported using a doctor, family and friends, and television to obtain at least a moderate amount of information on

health matters. However, compared with people attending a general practice, they were less likely to obtain information from a doctor and the Internet, and were less likely to trust a doctor. *Socio-demographic characteristics* were important predictors for use of, and trust in, information sources. For people with schizophrenia: a higher level of educational attainment increased the likelihood of trusting the Internet as a health information source; living alone increased the likelihood of obtaining health information from television; and women with schizophrenia were almost seven times more likely than men to trust family and friends as providers of health information. There were positive correlations between the amount of health information obtained from a given information source and the level of trust invested in it (except for newspapers).

About 55% of participants with schizophrenia perceived at least a moderate risk to themselves associated with the H1N109 pandemic; 37.1% perceived a substantive likelihood of contracting swine flu, and 63.2% of all volunteers with schizophrenia believed it would be serious if they did contract it. Close to two thirds of people with schizophrenia believed they could avoid contracting swine flu. These risk perceptions were not statistically significantly different to those of adults attending general practice settings who did not suffer from schizophrenia. However, participants with schizophrenia were only about a third as likely as people attending a general practice setting, to demonstrate specific knowledge about influenza. Positive predictors of perceived overall risk from H1N109 for people with schizophrenia included (1) *perceived likelihood* of contracting the virus, (2) *perceived seriousness* of contracting the virus

(3) poor self-rated health, and (4) a predicted affective response of fear in the event of contracting swine flu. Negative predictors included (1) a predicted affective response of depressed mood if swine flu were contracted, (2) a higher K10 total score, (3) a higher K10 anxiety subscales score; and (4) a K10 total score ≥ 20, versus < 20.

The majority of participants with schizophrenia reported being at least moderately willing to be vaccinated (74.3%), isolate themselves (73.2%), wear a face mask (54.9%) and increase hand washing (88.6%). However, compared with people attending a general practice, they were less likely to be willing to receive a vaccination or to isolate themselves. They were more likely to perceive vaccination as risky for adverse events and more likely to be concerned about 'catching the flu' from a vaccination. Predictors of willingness to adopt precautionary measures, for people with schizophrenia, included risk perceptions about H1N109, beliefs about the effectiveness of a given protective measure, and self-efficacy. For people with schizophrenia the most commonly perceived barriers for vaccination were concern about side effects (36.6%), cost (28.2%) and transport to a health facility to receive the vaccination (19.7%); for isolating oneself were loneliness/missing social contact (38.0%), accessing food and groceries (22.5%), and boredom (18.3%); for wearing a face mask were appearance / stigma (32.4%), the discomfort of the mask (16.9%), and difficulty breathing (15.5%); and for increased hand washing were access to facilities to wash (29.8%), concerns about skin irritation (15.1%), and having the time to do it (14.7%).

<u>(2) Qualitative study with in-depth interviews</u>

In order to obtain richer and more personalized data relating to the research aims outlined above, a qualitative study was carried out (August 2014) to supplement the cross-sectional survey. Eleven adults (six male) with schizophrenia engaged in treatment at a community mental health centre in the ACT, were interviewed individually, using a topic guide but with the adoption of a flexible and responsive conversational approach. Key findings included:

(1) participants identified a need for information on characteristic symptoms of influenza enabling a person to distinguish between a 'cold' and 'flu'

(2) the presence of a large range of "illness experiences" associated with contracting influenza

(3) important roles for trust in general practitioners to advise on need for vaccination, and to provide a physical 'checkup'

(4) strong endorsement of vaccination and hand washing as key protective measures

(5) belief in non-evidence based 'alternative' medicine did not preclude engagement with a general practitioner and willingness for vaccination

(6) provision of knowledge on how to protect against a circulating influenza, including whether a vaccination is necessary, was viewed as important information for people to know

(7) public messaging about influenza through written information (e.g. posters) in public places, and on television, was viewed as important

(8) low levels of concern and risk perception during the 2009 swine flu pandemic

(9) low risk perception of a possible future influenza pandemic, including 'bird flu', suggesting *possible* complacency

7.3 Review of hypotheses

In this section, the five a-priori hypotheses are reviewed in light of the research study findings.

Hypothesis 1:

People with schizophrenia report obtaining less health information from common information sources compared with people attending a general practice setting who do not have schizophrenia.

This hypothesis was partly supported. People with schizophrenia reported obtaining less health information from doctors and the Internet compared with people attending a general practice setting but there were no statistically significant differences for television, radio, newspaper, magazines and family and friends (when potential confounders were adjusted for).

Hypothesis 2:

People with schizophrenia have less trust in common health information sources compared with people attending a general practice setting who do not have schizophrenia.

This hypothesis was partly supported. The research study revealed that people with schizophrenia appear to have less trust in doctors than people attending a general practice setting. However, there were no statistically significant differences for the Internet, television, radio, newspaper, magazines or family and friends.

Hypothesis 3:

People with schizophrenia have a higher risk perception of a pandemic influenza compared with people attending a general practice setting who do not have schizophrenia.

This hypothesis was not supported. There were no statistically significant differences between people with schizophrenia and people attending general practices with respect to perceived risk of oneself contracting swine flu, perceived seriousness if one did, or in personal vulnerability to the swine flu pandemic. Whether this would have still been the case if the viral strain causing swine flu had been hypervirulent, like the highly pathogenic H5N1 strain, is unable to be deduced from this research project and could be the focus of future research.

Hypothesis 4:

People with schizophrenia are less willing to undertake protective measures against a pandemic influenza than people attending a general practice setting who do not have schizophrenia.

This hypothesis was partly supported. The thesis study found that people with schizrenia expressed significantly less willingness to be vaccinated and to isolate themselves, if advised to by government health authorities, compared with people attending a general practice. As with hypothesis 3 above, one might speculate that this may possibly not have been the case if the causative viral strain had been hypervirulent with a high reported mortality rate.

Hypothesis 5:

People with schizophrenia report a different ranking of perceived barriers to carrying out protective measures against a pandemic influenza to people attending a general practice setting who do not have schizophrenia.

This hypothesis was partly supported. There were differences in the ranking of the three most commonly perceived barriers for vaccination, self-isolation and hand washing but no difference for wearing a surgical face mask. These differences are not surprising and are congruent with differences in socio-demographic characteristics between the two groups. For instance, attending work or university was frequently identified as a barrier by people in the GP group for self-isolation but much less so for people with schizophrenia. A problem with transport to a health facility to receive a vaccination was perceived as significant problem for many people with schizophrenia but almost non-existent as a perceived barrier for participants without schizophrenia. These differences reflect disparities in *socio-demographic profile* between people with schizophrenia and people attending a general practice setting without schizophrenia.

7.4 Strengths and limitations

Strengths

Pandemic influenza has the capacity to kill a very large number of people in a relatively short passage of time, and has been identified as one of the most potent threats to society in the 21st century. Therefore, one of the strengths of the research project is that it addresses an important and relevant issue. The timing of the H1N109 pandemic provided a unique opportunity to examine people's responses to a pandemic in "real time" during an actively evolving event. Another strength of research project is that its focus is people with an illness that imposes considerable vulnerability in the event of a pandemic vulnerability.

The research project used two data collection points, a cross-sectional survey (with qualitative and qualitative elements), and a qualitative study using in-depth interviews. Although the survey study involved a 'non-probability' sample, it was a purposive "real world" sample, with both groups of participants attending a health care setting. The thirteen general practices were chosen from different geographical settings generating a range of socio-demographic characteristics. Most of the questions relating to risk perception and willingness to carry out protective measures had been field-tested and found to be reliable in a previous study. The inclusion of open-ended questions increased the likelihood of obtaining more personalized, detailed and unbiased responses from participants. Due to controversy over how best to analyze

Likert data, both parametric and non-parametric statistical tools were employed.

People with schizophrenia have often been placed at considerable disadvantage by being omitted from research examining important physical health issues, including studies exploring what people think and feel about key aspects of their health and relevant health threats. The thesis research project was a deliberate choice to take a positive public health approach to addressing the increased risk of people with schizophrenia to influenza, with a focus on pandemic influenza. The thesis studies have been able to fill in important gaps in the current knowledge base with respect to people with schizophrenia. They are the first studies to have examined the perception of risk, willingness to engage in protective behaviours and associated perceived barriers during an influenza pandemic, in a sample of people with schizophrenia. They are also the first studies to have explored what information sources people with schizophrenia report using to obtain health information, and their levels of trust in these sources. It is important that people with schizophrenia receive evidence-based and appropriately communicated health information in relation to pandemic influenza, but also more broadly. As discussed in chapter one, people with schizophrenia are more likely to smoke, misuse alcohol, use illicit drugs, be obese, eat a diet high in fat and low in fibre, and to have significant comorbid medical disorders, than people in the general population. Therefore, it is important that they access the necessary health information related to these issues. People with schizophrenia have often been stigmatized and

marginalized. The thesis research project findings provide further support to endeavours that try to ensure they are not excluded from health programmes.

Limitations

The following is a summary of the main limitations of the cross-sectional study. The limitations of the qualitative study have been described in chapter six. Recruitment bias exists with self-selection and the employment of non-probability and cluster sampling, limiting the generalizability of the findings. The sample size of the schizophrenia group of volunteers was relatively small compared with the number of participants attending a general practice setting. Educational attainment in the Australian Capital Territory is significantly higher than elsewhere in Australia, again impacting on the ability to generalize the results. Case ascertainment in the schizophrenia group was by treating consultant psychiatrist diagnosis rather than employing a diagnostic instrument (although it could be argued that this is a strength, increasing the likelihood of an accurate diagnosis). Likert scales, the principal measure used in the study, have inherent limitations including central tendency bias and social desirability bias. The survey did not include a screening test to identify and quantify possible cognitive impairment that may have impacted on how items in the questionnaire were answered. However, cognitive impairment was not the focus of the thesis, which was aimed at eliciting the views and perspectives of people with schizophrenia living normalized lives in the community who had the capacity to participate (and compare these with people attending a primary care setting). With the exception of one potential participant (at the

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rehabilitation centre), who was clearly not able to comprehend items in the questionnaire and who was excluded from the study, there was no evidence in the returned questionnaires that any volunteer did not have capacity to give informed consent or to engage and answer questions in the survey.

Other limitations include: asking people what they are *willing* to do may be at variance from what they *actually* do; risk perceptions for individuals might vary over time requiring a longitudinal study to detect this. Comparison of the present study findings with those of avian influenza risk perception research presents challenges due to marked differences in case fatality rates.

7.5 Practical implications

The research study has given rise to a number of important practical implications, which may be helpful in pandemic influenza preparedness and response planning, and for public health policy more broadly:

(1) Groups that have been identified by health authorities as being 'vulnerable' during an influenza pandemic include pregnant women, people of indigenous cultural background, immuno-compromised individuals, obese patients, and people with significant medical disorders such as chronic pulmonary disease, diabetes mellitus and heart disease. The literature review in chapter one provided compelling grounds for including people with schizophrenia as a potentially vulnerable group during a pandemic influenza, given their significant levels of medical comorbidity, smoking, alcohol misuse and obesity. Therefore,

the findings in the present study could inform preparedness and response planning for a future influenza pandemic. Given that the study revealed substantive willingness of people with schizophrenia to receive a vaccination during a pandemic if advised by government health authorities, but identified cost as a major perceived barrier, provision of free vaccination in mental health facilities for people with schizophrenia could be an effective component of a pandemic action plan. More generally, there are likely to be gains from public health policy initiatives aiming to broaden medical education about mental illness, especially with respect to its significant impact on physical health and need for engagement in public health campaigns.

(2) Given that "side effects" was the most commonly perceived barrier for receiving a vaccination, provision of clear information, and opportunity for discussion, about the risk benefit profile of influenza vaccinations is likely to be useful. This could be provided by the patient's general practitioner, or perhaps by a clinician working at a community mental health centre. Given the finding in this study of 72% of participants with schizophrenia reporting concerns about "catching the flu" from a vaccination, the risk benefit discussion would need to include exploring, and correcting if necessary, any misconceptions about a killed vaccine causing influenza.

(3) Given that the third most commonly perceived barrier to receiving an influenza vaccination during a pandemic, for people with schizophrenia, was travel to a health care facility, assistance with transport is likely to be a helpful

intervention. Alternatively, the vaccine could be administered on a home visit from a community mental health clinician. These measures are likely to increase the uptake rate of vaccination for people with schizophrenia, with gains not only for those individuals but also for the community at large, by decreasing rates of viral transmission.

(4) Given (i) the strong evidence for the efficacy of hand washing in preventing transmission of respiratory viruses (described in the literature review in chapter two), (ii) the reported willingness of people with schizophrenia to increase hand washing during a pandemic influenza, both in the survey and in the in-depth interviews, and (iii) lack of facilities (e.g. basins) reported as the most common perceived barrier to hand washing found in the present study, encouragement to use and/ or the provision of, alcohol-based antiseptic gels, could be helpful. These are effective against influenza viruses and do not require a basin or sink, as water is not needed for their use. Again, there are potential benefits arising from these measures not just for individuals with schizophrenia but also for the whole community by reduction in rates of viral spread in the general population. As "not remembering" was a commonly identified perceived barrier for hand washing, well placed information posters promoting hand hygiene in community settings, such as schools, hospitals and shopping centres, as well as in health professionals' waiting rooms, is likely to be helpful. The current National Hand Hygiene Initiative is implementing measures to increase awareness of hand hygiene and promote its uptake in health professionals, but also in the community at large. It is important that these campaigns are

designed and implemented in such a way that marginalized groups, such as people with schizophrenia, are not excluded, from their potential benefits. Assertive outreach of these programmes to public mental health centres and psychiatric inpatient and rehabilitation settings is essential.

Parallel messages for washing hands

There are parallel gains related to hand washing in addition to reducing the spread of influenza infections, for both people with schizophrenia and the community at large. Infectious diseases as a whole constitute a large proportion of the global burden of disease, with diarrhoeal diseases being the single greatest contributor of any medical disorder. Susceptibility and sensitivity to infection in general relate to multiple factors including biological and psychological profiles, political and economic restraints on health systems, and societal norms and beliefs. However, most infections are preventable and hand washing is the primary measure to reduce infections (World Health Organization. WHO Guidelines on Hand Hygiene in Health Care 2009).

Therefore, in addition to reducing the risk of contracting influenza or spreading influenza in the community, there are added gains for good hand hygiene in general, including reduction in other conditions such as gastrointestinal, skin, and ocular infections, and reduced risk of ingesting toxic substances if handled. As such a simple procedure the cost-effectiveness is clear. Hand washing is also associated with combating the ever-present threat of microbial resistance. Poor hand hygiene is considered to be the leading cause of rates

of multidrug-resistance organisms, which place everyone in society at risk but particular those with increased vulnerability, such as people with schizophrenia.

Hand hygiene can be developed a 'good habit' starting in childhood. Therefore, both families and schools can paly a role in educational and monitoring processes with children. Hand hygiene promotion has been shown to improve child health and reduce rates of respiratory tract infection, diarrhoeal disease and impetigo (World Health Organization. WHO Guidelines on Hand Hygiene in Health Care 2009).

In addition to the concrete gains described above, regular hand washing may play a psychosocial role, by giving people a sense of self-efficacy and empowerment over threats in their environment. It is something simple to perform that can be integrated into a healthy lifestyle regimen. This is likely to be particularly important for people who often feel a sense of deprivation and disempowerment, such as those with a mental illness.

(5) As people with schizophrenia are often socially isolated and marginalized, additional social and psychological support may need to be provided if there is a requirement for isolation at home during a pandemic. A substantive number of people with schizophrenia identified loneliness and missing contact with their friends as perceived barriers for self-isolation at home. Approximately one third of participants with schizophrenia in the study lived alone. Therefore,

restrictions imposed on opportunities to visit friends and family during a pandemic (an event which may independently contribute to psychological stress) may negatively impact on level of wellbeing or cause frank exacerbation of psychosis or existing comorbid psychiatric illness.

(6) There is a need for targeted communication strategies delivering clear, accurate and timely information about the nature and progress of the pandemic, associated risks and recommendations about implementation of protective measures to patients and to people more generally in the community. The thesis study revealed that people with schizophrenia had substantive levels of reported adherence to most protective measures if recommended by government health authorities. Therefore, it may be helpful for clinicians in any health care setting, when assessing or reviewing a patient with schizophrenia, to allocate time to exploring whether or not there is an awareness of public messaging about a prevailing or imminent pandemic outbreak. If not, then a verbal or written (e.g. pamphlet) information on this health message could be provided.

(7) Given that people with schizophrenia viewed their 'family and friends' as important and trusted sources of health information, family members and friends of patients with schizophrenia appear to be well placed to assist in the information delivery process during a pandemic influenza. This assistance could involve passing on, and discussing, the contents of information

pamphlets provided by a general practitioner, health authority or mental health clinician.

(8) The thesis survey findings suggested that people with schizophrenia have poor factual knowledge of the symptoms and duration of influenza. Resonating with this was a theme in the in-depth interviews that important information for people to know is how to distinguish a 'cold" from 'flu'. It may be helpful for public health services, particularly in the early phases of an influenza pandemic, to target this vulnerable group with educational assistance in terms of what symptoms to be vigilant for, and what action should be taken if these symptoms occur. A prominent theme in the in-depth interviews was a request for written information at public places, such as bus stops, perhaps in the form of posters. Both the survey and the in-depth interviews suggested that television is a medium where people with schizophrenia learn about important prevailing health issues, such as circulating influenza. Therefore, public messages on television are likely to be helpful.

(9) As discussed in chapter five, given the important and dynamic role e-health is likely to play in the future, and the suggestion of under-utilization of the Internet as a source of health information in the present study, providing assistance on skills to use computers and other electronic devices such as 'tablets' and 'smart phones', is likely to be helpful. For many people with schizophrenia owning or renting a computer or other electronic device may be cost-prohibitive. Therefore, providing free Internet access for people with

schizophrenia in settings such as mental health 'drop-in' day centres may be useful. An effective strategy may be the development of community health programmes that utilize electronic resources but have strong links with treating clinicians, especially in integrating physical and mental health. People with schizophrenia are sometimes perceived in the community as being somehow fundamentally different from others, and may, as such, be marginalized and placed at a disadvantage in general community health programmes. Treating clinicians from difference disciplines may be able assist in linking people with schizophrenia to community educative programmes that have the most relevance to them. This may include programmes, or 'apps', that provide information and advice on lifestyle choices as well as protective strategies against a range of potentially preventable diseases. Ensuring that people with schizophrenia, and other marginalized groups, are not 'left behind' in the progressively more technological world of the future, is also symbolic of a compassionate society's core values of equity and egalitarianism.

Summary of profile and recommendations for people with schizophrenia

The thesis study provided evidence that people with schizophrenia are prone to social disadvantage and impoverishment. Socio-demographic data revealed them to be, as a group, less well-educated, more likely to be unemployed and living alone, less likely to have children in the household, and more likely to be living in households with a lower income, compared with people attending a general practice setting. Fewer than one in four participants with schizophrenia in the thesis study were employed, less than 10% had attained a university

degree, and close to three quarters lived in households where the estimated annual (gross) income was less than $20,000 a year.

In light of these important socio-demographic characteristics, as well as the study findings in general, an assertive public health approach seems best placed to mitigate the risks of influenza, especially pandemic influenza, as well as aiming to assist people with schizophrenia in improving their physical health more broadly. Recommendations are discussed below:

(1) Targeted communication strategies are required to bring about, or increase, awareness of the emergence, nature and progress of, any serious or potentially serious outbreak of influenza, as well as effective protective measures, especially the inclusion of people with schizophrenia in public campaigns promoting the efficacy and simplicity of hand hygiene as a protective measure. Given that doctors and television are frequently used and trusted health information sources, messaging strategies could utilize them. Posters and other forms of written information provided in public places and doctors' surgeries, have also been identified by people with schizophrenia as helpful. Messages would need to be communicated in a clear, simple and practical way. In order to best assist people with schizophrenia, mental health services may need to be more proactive in the identification of patients' specific and general needs in response to emerging public health threats.

(2) Assistance with funding and implementation of influenza vaccinations that are seen as appropriate by experts in the field, is recommended; provision of information on, and the opportunity to discuss, the risk benefit profiles of these vaccinations, including adverse reactions, is essential.

(3) The development of educative programmes and assistance with access to e-health strategies to improve general health, as well as to reduce risks associated with influenza and risk factors for COPD, diabetes and ischaemic heart disease is recommended. These would need to include advice and programmes on modifiable lifestyle factors such as smoking, overeating, under-exercising and alcohol over-ingestion. Measures to improve access to the Internet more broadly may also help people with schizophrenia to reduce their sense of social isolation and disconnectedness.

(4) The development of strategies to increase engagement of people with schizophrenia with their general practitioners, not only as sources of health *information* but also to provide *encouragement and motivation* to engage in protective actions against health threats and vulnerabilities; this could include taking steps to enable community mental health centres having general practitioners, dieticians and possibly nurse practitioners working onsite. General practitioners might be involved with promoting 'quit smoking' programmes, healthy lifestyle choices, and possibly cardio-metabolic clinics. There is evidence that successful interventions exist to help address unhealthy lifestyle behaviours in people with schizophrenia. For instance, a recent

Cochrane systematic review (Tsoi et al. 2013) examined 34 randomized trials of cigarette smoking cessation or reduction, comparing pharmacological or psychosocial interventions with placebo or another control, in adults with schizophrenia or schizoaffective disorder. Bupropion was found to increase smoking abstinence rates in people with schizophrenia, without side effects to their mental state. Varenicline was also associated with an improvement in smoking cessation rates in people with schizophrenia, but with possible adverse psychiatric side effects. Contingent reinforcement with money appeared to help with people with schizophrenia to quit or reduce smoking in the short term but there is uncertainty whether these benefits are maintained in the longer term. A systematic review conducted by Hjorth et al. (2014) examined controlled interventions (dietary, exercise and cognitive behavioural therapy) aimed at reducing overweight and obesity in adults with schizophrenia. Results indicated that these interventions have efficacy in reducing weight and improving physical health parameters in people with schizophrenia.

(5) Provision of antiseptic gels (which don't require water for their use) in hospitals and mental health facilities generally, as well as encouragement to use them at home and at work, is recommended.

(6) In the event of a pandemic influenza, and the potential requirement for isolation at home, there may be the need for provision of extra psychological

and social support during this potentially destabilizing time, for a person with schizophrenia.

(7) Although not participating in the thesis study, severely handicapped people with schizophrenia also need to be considered in public health programmes aimed at attenuating the negative impact of seasonal and pandemic influenza. Vaccinations, appropriate hand hygiene and other protective measures are likely to be pivotal in minimizing adverse medical outcomes during influenza outbreaks. Public health programmes may need to involve carers, support workers, general practitioners and mental health clinicians in provision of these protective measures, and guardianship or Power of Attorney, may be required.

(8) Encouragement and assistance (e.g. by community health teams and family) in the establishment and maintenance of close links with a GP, to provide health information about influenza and more broadly, and to provide optimal management (including primary and secondary prevention) of chronic medical disorders and unhealthy lifestyle issues (if present), which exacerbate the risk of complications, including death, from influenza/pneumonia. Provision of a physical 'check-up' is also seen by people with schizophrenia as an essential role for the GP if influenza has been contracted.

(9) Broadening medical education about the negative impact of mental illness on physical health and engagement in public health campaigns is important. This could target medical students, as well as students in allied health study

courses such as nursing, dieticians, occupational therapists and others. In addition, it could be included as part of continuing professional development / medical education activities in medical specialties and in programmes for other health workers, health educators and administrators.

Summary of profile and recommendations for people without schizophrenia attending a general practice setting

The thesis study revealed a much more favourable socio-demographic profile for people without schizophrenia attending a general practice, compared to people with schizophrenia attending public mental health facilities. As a group they were highly educated with close to half having attained a university degree. Over 90% were employed and just over half lived in households earning more than $80,000 (gross) annually. There was a suggestion of significantly greater social connectivity compared with people with schizophrenia, with only 12.2% living alone, and nearly 45% having children in the household. As with people with schizophrenia, about one in five people attending a general practice setting in the ACT, lived in a household where a language other than English was spoken.

Recommendations for people without schizophrenia, attending a general practice setting, are discussed below.

(1) Unsurprisingly in light of these socio-demographic characteristics, a substantial proportion of people without schizophrenia attending a general practice setting obtained health information from, and trusted, doctors and the

Internet. Therefore, communication of the emergence, progress and required protective actions in the event of a pandemic influenza, could utilize these sources. Although less popular, television and radio, are also likely to also be useful.

(2) Given that perceived effectiveness and (adverse reaction in the case of vaccination) were important predictors of willingness to carry out protective measures for this group, public educative processes and campaigns which emphasize their effectiveness, perhaps especially regarding vaccination and hand-washing, are likely to be helpful. These could utilize posters in areas like the work place, public libraries, shops, hospitals, and doctors' surgeries. The Internet is well placed to play an important role, in addition to television and radio mentioned above.

(3) Given that *time* was an important perceived barrier to vaccination in this group (almost equaling *side effects* in frequency, as a reported barrier) and the high levels of employment, provision of vaccination at the work place is likely to be helpful (this is already operative in some work settings).

(4) Time away from university or work, were frequently cited barriers to self-isolation at home. Therefore, availability of lectures and learning material online may assist in this regard.

(5) Given that by far the commonest perceived barrier for wearing a facemask was appearance and stigma, public messaging aimed at destigmatizing facemasks, would be useful.

(6) Provision of antiseptic gels in schools, the workplace, at universities and public facilities, as well as encouragement for their use in private settings, is strongly recommended.

7.6 Broader Issues and implications

The thesis findings raise broader issues including the *relationship between socio-economic status and health behaviours*, *mental health specificity*, and *trajectories of mistrust in medical practitioners.*

(1) Socio-economic status and health behaviours

As reflected in the descriptives in the thesis cross-sectional study there are significant disparities in socio-economic status (SES) in people with schizophrenia compared with people from the general population. In light of the **inverse relationship** between **SES** and **unhealthy lifestyle behaviours** , and in order to better target and assist vulnerable groups, it is relevant to explore possible causal mechanisms between these two domains, in an attempt to disentangle them. Pampel et al. (2010) and Cutler & Lleras-Muney (2010) have published helpful critical analyses of these issues.

SES is a multidimensional construct comprising education attainment, income, wealth, employment, and nature of occupation (Pampel et al. 2010). These elements of SES interact with each other and are not static but rather may undergo variation throughout the lives of people with schizophrenia and other illnesses. Gender also has an impact on the relationship between SES and health behaviours. For instance, women tend to have a later onset of schizophrenia, and less severe presentations, and therefore, may have completed socialization and educational processes, including possible tertiary qualifications, before the onset of their illness. This higher educational attainment may then have a bearing on employment status and income and related health behaviours, especially if there has been successful treatment and rehabilitation. In addition to components of SES interacting with each other, elements of lifestyle may influence each other, in either a positive or negative direction. For instance, replacing a sedentary lifestyle with regular exercise may facilitate weight loss and cessation of smoking, whereas quitting smoking may be associated with weight gain.

There is little doubt about a correlation between SES and unhealthy behaviours. Studies of the US general population, with samples sizes of up to approximately 23,000 have revealed clear differences for smoking, lack of exercise and obesity (BMI $\geq$ 30) associated with SES (Pampel et al. 2010). For instance, even after controlling for age, gender, race and foreign birth, a low income earner was almost twice as likely to do "no exercise" compared with someone on a high income. The regression analysis findings were more

marked for smoking and lack of exercise than for obesity, and educational attainment was the strongest predictor among the SES components. There was a three percentage point lower probability of smoking for every year of education completed. In the context of smoking being the leading cause of preventable death in Western world (accounting for 18% of all deaths in the US), this is a very important finding (Mokdad et al. 2004). Similarly, obesity (which has been estimated to be the second most common preventable cause of death) was found to be reduced by 1.4 % for each additional year of schooling (Culter & Lleras-Muney 2009). However, it should be noted that important as they are, health behaviours are not the only determinants of disparities in health outcomes between people of different socio-economic status. Research has demonstrated that even after controlling for relevant health behaviours, there remains a significant amount of variation in health outcomes associated with socioeconomic factors (Dunn 2010).

Given that the strong link between SES and health status has persisted over time despite advances in medical diagnosis and treatments, changes in the causes of mortality profiles, and new public health initiatives, there is unlikely to be just a single mechanism mediating the relationship (Lutfey & Freese 2005). On the contrary, the relationship appears to be complex and bidirectional. Pampel et al. (2010) point out that SES represents more than just the financial ability to purchase goods and services that are health promoting. For instance smoking can be expensive while some forms of exercise such as walking are free.

Income

A key feature of SES is income. Low income and/or financial constraint may impact on healthy behaviours in several ways. It may act by reducing access to resources or services that promote good health or assist with quitting an unhealthy aspect of lifestyle. For instance, people who earn more may be capable of accessing gymnasiums for regular exercise and a personal trainer to encourage motivation and give advice on exercise schedules. They are more likely to be able to afford certain highly nutritious foods such as salmon with ample levels of omega-3 oils, enjoying the associated health advantages. Furthermore, they are more likely to be able to afford health insurance (especially important in the USA as discussed in chapter one) facilitating contact with a doctor or other clinician resulting in an increased exposure to advice, knowledge and motivational discussions relating to preventative medicine strategies. Cross-sectional surveys reveal that people receiving low incomes frequently report that 'money' is a major barrier to accessing medical care (Cutler & Lleras-Muney 2009). Particularly pertinent preventative measures in Western societies include identifying and managing vascular risk factor for coronary heart disease and stroke, diet and exercise to avoid (or manage already existing) obesity as a risk factor of diabetes type II (and other diseases), and vaccination and hand washing to protect against influenza. Higher income or existing wealth also permits recruitment of resources to assist in quitting unhealthy behaviours such as smoking, through counseling, nicotine replacement therapy or hypnotherapy, which may be cost-prohibitive to a person in a low SES group.

Some authors have suggested a psychological context for the relationship between low income / financial constraints and unhealthy lifestyle (Lantz et al. 2005; Layte & Whelan 2009; Pampel et al. 2010). They posit that the financial adversity associated with low SES drives behaviours such as smoking, overeating and under-activity as forms of mood regulation, providing pleasure, relaxation and respite from the psychological stress engendered by the constant strain of trying to make ends meet. Studies exist which support a link between psychological stress and unhealthy behaviours, including increased smoking (Johnson & Hoffman 2000), higher levels of fat consumption and reduced mild, moderate and high levels of exercise (Ng &Jeffery 2003; Burdette & Hill 2008). It has argued that the socio-economic gradient in health behaviours, and stress responses to poverty, may be linked to an individual's early developmental years (Dunn 2010). Self-regulation and executive function are important in governing health behaviour and may be influenced by socio-economic status. Research exists which suggests that children of lower socio-economic status are more likely to have deficits in self-regulation and executive function, supporting the view that the experiences of the stress associated with low SES, and unhealthy behaviours, may have common roots early in life (Farah et al. 2006; Dunn 2010).

Research examining the relationship between the low income / financial stress and adverse health behaviours, faces certain challenges. The first is that of direction. Although, as explored above, low income and poverty may provoke unhealthy behaviours, the reverse may also be true. For instance, a person

who enjoyed a favourable income may have become unwell *due to* adopting unhealthy lifestyle choices, with *subsequent* loss of job and resulting financial loss and poverty. In addition, there is some evidence that despite people with low SES being exposed to more, or more intense, stressors, they also report lower levels of perceived stress compared with people with high SES profiles (Kruger & Chang 2008; Pampel et al. 2010). Finally, there is evidence that a person's *perceived* income inequity is more important than their actual income. The absolute magnitude of an individual's income and material assets in one country, or region of a country, may constitute low SES, but in another more socially impoverished setting may represent relative wealth. Siahpush et al. (2006) found that high levels of *perceived* income inequality was associated with higher levels of smoking, whereas Chang & Christakis (2005) found no positive correlation between *actual* income inequity and being overweight or obese.

Education

Education as a component of low SES may have several associations with health behaviours. High quality education at school (and in the home) may impart not only *knowledge* about health issues but may also help cultivate *curiosity* and a desire for *life-long learning*, as well as developing information processing and problem solving skills. Pampel et al. (2010) suggest it may also improve the *locus of control* needed to combat smoking addiction, craving for unhealthy foods, the "discomfort" of exercise and the "inertia" of inactivity. School and tertiary education may not only influence a person to seek

information during their life but equip them with the skills to find it and to process and make sense of it. Research has revealed that about half of people with at least some tertiary education obtain their most 'useful' health information from books, magazines or newspapers compared with 18 percent among the less educated (Cutler & Lleras-Muney 2010). Cutler & Lleras-Muney (2010) point out that education does not only exert its effects through better knowledge but also through other pathways including: better conceptual thinking; translating intentions into actions; better utilization of health resources, and improved social networking.

The influence of knowledge on health behaviour is changing over time. It has been argued that less well educated people of lower SES may have jobs which provide less opportunity for learning, including about the detrimental effects of unhealthy lifestyle, and that this results in less motivation to adopt healthy behaviours (Pampel et al. 2010). They are more likely to be exposed to advertising which promotes the 'pleasurable' aspects of smoking and unhealthy food, and less likely to be exposed to health warnings about the long-term dangers of smoking, sedentary habits and poor nutrition (Siahpush et al. 2006b). However, despite evidence supporting poorer knowledge of the harmful effects of smoking in lower SES populations in the past (Link 2008), more recent research has indicated that this disparity has lessened over time. This is likely to be due to improved public messaging, anti-tobacco campaigning, the non-smokers rights movement, government initiatives to prohibit smoking indoors and raise prices of cigarettes, and the funding of

media promotion against smoking (Warner 2005; Pampel et al. 2010). However, although knowledge about the health promoting effects of exercise and sleep has also begun to transcend SES profile, knowledge of the potentially harmful consequences of obesity is less ubiquitous, with continuing SES disparities. While 86% of US adults reported believing that lack of sleep was bad for their health, and 63% viewed exercise as a highly important activity for a health lifestyle (Lyons 2005; Pampel et al. 2010), as little as 36% of US adults viewed obesity as a very serious health problem (Bleich et al. 2007).

Occupation and class distinction

Although occupation is often a determinant of income, it represents a discrete component of SES in its own right. For instance, a judge and a successful used car salesman or saleswoman may receive similar incomes but in many societies being a judge may confer a higher social standing, and be a marker of social distinction. There may be greater social 'pressures' associated with this higher class distinction to adopt, and be seen to adopt, a healthy lifestyle, both from within and outside the profession. Interestingly, early in the 20th century, it was higher SES groups who took up smoking, perhaps as a form of innovative trend or fashion setting or to emphasize their class distinction (Pampel 2005; Pampel et al. 2010). Pampel et al. (2010) raise the possibility that lower SES groups may, conversely, deliberately adopt unhealthy lifestyle choices to frame themselves as "tough" and independent individuals, not allowing themselves to be controlled by convention. Certain occupations, such

as sportsmen/women or those in health promotion may experience a degree of cognitive dissonance associated with living an unhealthy lifestyle, as well as witnessing higher levels of judgement or more stigmatizing attitudes from their peers in this context.

Other factors

There are several other factors that may play a role in linking SES with unhealthy behaviours and lifestyle. In keeping with health behaviour models such as the Theory of Reasoned Action (Fishbein & Ajzen 1975) peer influence and social cohesion are important factors in lifestyle choices and health behaviours. A person's perception of how others view a health behaviour, and the willingness of the person to conform to these views, are key elements. People in higher SES groups are more likely to have social networks that support and promote health behaviours. Peer influence appears to be particularly relevant to young age groups, especially adolescents, where the smoking of friends is one of the strongest predictors of smoking (Jacobson et al. 2001).

It has been argued from an economics, epidemiology and sociology base, that people in low SES groups have less to gain from healthy lifestyle behaviours in terms of investing in future longevity, due to lower lifetime earning and wealth (Pampel et al. 2010). Therefore, they are more likely to be influenced by their present circumstances in making choices about health behaviours rather

than adopting a futuristic approach. For instance, an increase in cigarette prices tends to reduce smoking more in low SES groups (Thomas et al. 2008).

Another factor is *community and environment*, although this relates in part to income, wealth and possibly nature of occupation. Low SES *neighborhoods* are often the focus of tobacco companies for outdoor advertising campaigns (Barbeau et al. 2004) and frequently have a higher density of fast-food outlets (Maddock 2004; Cummins at al. 2005) with associated increased risks for smoking and obesity, respectively.

Finally, it is possible that personality traits exist which increase the probability of both being in a low SES group as well as having harmful health behaviours. Traits comprising high novelty seeking, reduced tolerance for delayed gratification, and high impulsivity may act impact on SES (through a negative effect on educational and employment opportunities) as well as harmful behaviours such as smoking, substance use and overeating with preference for foods with a high sugar and/or high fat content. It has also been argued that low general intelligence may be a trait that spuriously links low SES with unhealthy behaviours. However, there is little evidence for this and controlling for intelligence has been found not to significantly weaken the relationship between low SES and health (Link et al. 2008).

Gender

There are well-established gender differences in health. Although varying across nations, gender differences exist in mortality and life expectancy. In most developed countries women tend to live longer than men, with lower rates of leading causes of death including heart disease, cancer and stroke. In Australia, life expectancy for males is approximately 79.5 years, and 84.0 years for females. These gender disparities in health reflect both biological and health behaviour differences and the interplay between them.

In Western countries, men tend to have higher rates of potentially health-damaging behaviours, including smoking, being overweight, alcohol misuse, firearm use, hazardous occupations, and more risk-taking in driving and recreational activities (Waldron 2000).

In Australia, although there are still higher rates of smoking in males (compared with females) aged over 18 years (23% versus 19%), the gap is narrowing. In recent years, young women are now more likely to smoke than young men (24% of females aged 12-24). Compared with men, women are more likely to smoke as a means of dealing with stress, find it more difficult to quit, and seek more social support than men when quitting (Australian Government, Department of Health, Lifestyle Risk Factors 2011).

One of the current health threats in facing many Western nations is an obesity epidemic. Again there are key gender differences. In Australia about 70% of

males aged 18 years or over are either overweight (BMI > 25) or obese (BMI > 30). This compares with 56% of adult women. Despite this, Australian women report less regular physical activity than men (Australian Government, Department of Health, Lifestyle Risk Factors 2011). This difference in reported exercise is especially pronounced in adolescent and young women (only 30% of females aged 15-24 years exercise for at least 150 minutes per week). Some of the self-reported barriers to improving this health behaviour included time, caring responsibilities, low SES issues such as cost of particular activities, body image and concerns about personal safety.

Finally, It should be noted that gender differences differ among countries. As part of a large (n = 40,679) cross-sectional population study, Lazzarino et al. (2014) assessed the effect of gender on the association between low SES and unfavourable health behaviours (smoking, alcohol consumption, low fruit and vegetable consumption and physical activity) in the general adult population in England and Thailand. They found a positive correlation between low SES and unfavourable health behaviours in both men and women in England, no correlation in Thai men and a negative correlation in Thai women. These results may in part relate to differences in the social standing of women in lower-income countries, and the transition from rural to urban environments.

SES and health behaviours: targeting people with schizophrenia

The relationship between SES/gender and health behaviours has implications for public policy makers, health care providers and other relevant stakeholders,

when targeting vulnerable subgroups, such as people with schizophrenia. In the interests of striving for health parity in society, the following public health considerations arise from the discussion above:

(1) Removal or minimization of economic barriers to accessing health professionals and services through developing or maintaining health care systems which provide universal access, remains important. As described above, research studies have shown that people receiving low incomes frequently report that 'money' is a major barrier to accessing medical care. In order to acquire relevant health information, including preventative health strategies and healthy lifestyle choices, people in low SES groups, such as people with schizophrenia, need regular contact with a range of health professionals. In addition to medical practitioners, this might include psychologists, nurse practitioners, occupational therapists, rehabilitation workers and dieticians. In addition to health promotion and prevention, screening and early intervention are important. Given the higher prevalence of smoking, obesity and alcohol use, and the low level of bulk-billing in Australia, a useful policy change might include employing general practitioners and dieticians at public mental health centers.

(2) Given the effects of low income/wealth on accessing resources promoting healthy lifestyle discussed above, government funded 'packages' facilitating access to resources such as gymnasiums, swimming pools and weight loss programs, is worth considering.

(3) Implementation of public programs focusing on stress management strategies targeting low SES groups may be useful. As described above there is evidence for a link between *psychological stress* (generated by, or amplified by, financial constraints) and *unhealthy behaviours*, including smoking, high levels of fat consumption and reduced exercise.

(4) Policies and programmes that drive better education about the benefits of a healthy lifestyle, are indicated. These could take several different forms, including: compulsory inclusion of information about health behaviours in teaching curricula at public schools in an attempt to establish health-promoting patterns of behaviour at an early age; better constructed and delivered public messaging on television, radio, the Internet as well as on information posters in public places and health facilities.

(5) Government fiscal strategies such as increased taxation on the sale of cigarettes (and alcohol) and tax concessions for the sale and advertising of low fat / low sugar/ high nutrient foods. As discussed there is evidence that higher prices for cigarettes affect the purchasing behaviours of people with low SES more than those in higher SES groups.

(6) Government directed environmental and community/neighbourhood strategies to promote health lifestyle behaviours. These might include: ongoing 'clean air' laws prohibiting smoking in enclosed public places; restricting outdoor smoking and/or alcohol advertising that targets low SES

neighbourhoods; provision of free-access parks and other outdoor recreational areas within low SES communities; restriction of the number of fast-food and liquor outlets permitted in any given region of a city or town; and facilitation of the establishment of healthy food outlets.

These, and other, considerations are summarized in the overall public policy framework in Table 7.1, at the end of this chapter.

(2) Mental Health Specificity

Although people with schizophrenia are particularly vulnerable to influenza for the reasons discussed in chapter one, other mental illnesses may also confer increased risk with respect to influenza. Even though 'depression' comprises a more heterogeneous group of disorders than schizophrenia, there is evidence of unhealthy lifestyle choices and related chronic medical diseases in this population as well. Adults with major depression have higher rates of coronary heart disease and diabetes type II as well as increased rates of smoking, poor diet and lack of exercise compared with adults without depression (Katon 2003). For instance, in the US the CDC's National Health and Nutrition Examination Surveys (2005-2008) showed that 43% of adults with severe depression were smokers compared with 22% without depression (Pratt & Brody 2010). They also tended to smoke more heavily and were less likely to quit. Among people who smoked, there were close to twice as many depressed people than non-depressed people who smoked over a packet a day. As described in chapter one, smoking increases both the risk of

contracting influenza as well as the risk of medical complications arising from it.

In a record linkage study in Australia, people utilizing mental health services collectively (i.e. for any mental illness) had higher mortality rate ratios (5.4 for men and 3.4 for women) for the category *influenza and pneumonia* than for any other medical illness (Lawrence et al. 2001). When analysed illness-by-illness mortality rates for *influenza and pneumonia* were increased for many different mental disorders including major depression, affective psychoses, drug/alcohol disorder, and dementia. Interestingly, rates were reduced in the category *neurotic disorders*. Hospitalization rates for influenza, and also for pneumonia, were increased in depression, dementia and alcohol/substance disorders.

Similar to schizophrenia, other mental illnesses, especially if untreated, tend negatively impact on level of functioning, in a variety of domains including occupational, social, interpersonal, and self-care. This frequently results in altered socio-economic markers, for example, through loss of job or inability to complete educational trajectories. As discussed earlier this may then impact on health behaviours, and therefore present increased risk for influenza and pneumonia. Mental illnesses may also negatively impact on protective behaviours through their effects on a variety of pathways including poor motivation, disorganization syndromes, social isolation and marginalization, and cost and transport difficulties.

Physical disability is a very heterogeneous group of disorders but again may impact on risk of influenza and pneumonia through biological and psychosocial mechanisms. For instance, disorders such as cerebral palsy may directly affect swallowing function and thereby increase risk of aspirational chest infection. In addition, they are likely to negatively impact on occupational functioning and SES, with associated effects on access to resources and carrying out protective behaviours against influenza.

(3) Trajectories of mistrust in medical practitioners

The finding in the study of less likelihood of trust in a doctor as an information source, in people with schizophrenia compared with people in the general population raises the broader issue of trajectories of mistrust in medical doctors more generally.

Mistrust, as a construct, is complex and multidimensional. Aspects of a physician's behaviour, which may lead to mistrust by the patient, include dishonesty, incompetence, lack of compassion, failure to maintain privacy and confidentiality, lack of reliability and dependability, and poor communication. These dimensions have been included in various scales that attempt to measure trust/mistrust (Pearson & Raeke 2001). Although defining trust/mistrust is challenging, three key components are implicated. These include: (1) a degree of *vulnerability* of the *truster*, (2) uncertainty about the future actions of the *trustee*, and (3) a specific and valued *outcome or issue* (Rose et al. 2004).

Without some element of *vulnerability* there would be little or no need for trust. In the case of a patient's trust in a doctor, this *vulnerability* arises from factors such as: the illness itself and its associated symptoms and possible reduced level of functioning with a negative impact on achieving life goals; need for effective, but sometimes invasive, treatment; and an imbalance or knowledge and skills in the area of health. In terms of the second component, there would be no context for trust or mistrust if there were not different options for the physician to take in the management of a person's health. Therefore, in order for mistrust to be present, there must be an element of uncertainty or the possibility of different outcomes, some less favourable than others, which result from chosen actions taken by the doctor. Finally, there must be some object or issue that is entrusted to the trustee. In the case of a physician this is the physical and mental health and general well-being of the patient. *Mistrust* is sometimes conceptualized simply as the *absence* of trust. However, it can also be viewed as implying negative beliefs about the trustee deliberately acting in ways that are not in the best interests of the truster. This third component of mistrust may have a very narrow focus, such as the physician not keeping up to date with the latest treatments, or be more wide-ranging, such as having a tendency of being dishonest in not admitting errors that he/she has made.

Another important concept in any discussion of the trajectories of mistrust relates to how the trust or mistrust arises and evolves. Mistrust can be conceptualized as *expectant* or *experiential.* In the case of *expectant* mistrust, a person brings to the first consultation with a new physician, an attitude of, or

predisposition towards, mistrust of that physician (Goold 2002). Conversely, with respect to *experiential* mistrust, there may have initially been a sense of trust in a given physician, but over time this trust has become eroded and transformed into mistrust due to the repeated exposure to dishonesty, infidelity, incompetency, lack of compassion, breaches of confidentiality, poor communication, or lack of compassion. A similar distinction is the notion of *social* trust or mistrust versus *interpersonal* trust or mistrust. Social trust refers to trust in a *collective* institution whereas interpersonal trust describes trust in an *individual* as a result of developing a relationship with them. Apropos of this distinction, a person may have mistrust in 'doctors' as a group, but may have developed trust in a given doctor due to favourable experiences and the development of strong rapport over time.

There are historical and cultural trajectories that have impacted on mistrust in medical doctors. In much of the 19th century in America, trust was linked more with perceived personal integrity of the physician rather than accurate diagnosis and the delivery of effective treatment (Imber 2008). At leading universities prominent clergymen often gave graduation speeches urging doctors to pursue the development of "high moral character" to justify the trust placed in them by the public. However, in the late 19th century in America, the rapid ascendency of scientific medicine replaced, to a large extent, the religious influence on concepts of trust and mistrust. These scientific and technological advances, which shaped the practice of medicine in Australia in the 20th century, generated a new level of trust in doctors based on improved

ability to diagnose and treat illness. However, with the emergence of the civil rights movement and bioethics in the 1960s, society began to challenge their perception of doctors as being infallible, morally virtuous, and appropriately paternalistic. Together with unrealistic expectations about what doctors could achieve through scientific advances, this heralded a decline in trust in the medical profession.

This decline in trust has continued to the present time. Multiple factors have added to the decline including: better public access to medical information, facilitated by the advent of computers and the Internet, but also through better education in schools and more prominent public messaging; managed care and for-profit care in the US; closer media scrutiny and publicity surrounding medical errors, negligence, fraud, malpractice and abuse; public exposure of the undue influence of pharmaceutical companies and entrepreneurial medical centres sometimes driven more by desire for profit than striving for best practice. New transparency measures have even included a *MyHospitals* website to rank hospitals on their performance in Australia, and Internet *'Report Cards'* on the performance and outcomes of individual surgeons in the US.

The pivotal role trust plays in the relationship between doctor and patient has both *intrinsic* (i.e. importance in its own right) and *instrumental* dimensions. Its *intrinsic* significance as a core characteristic of a doctor-patient relationship, giving it meaning and substance, is highlighted by its prominence as a goal

and objective in medical ethics, health care law and public policy (Hall et al. 2001). The *instrumental* importance is reflected by the likelihood of less optimal health outcomes and trajectories occurring in association with mistrust.

If a patient mistrusts their doctor, it does not seem surprising that they may feel some reluctance following treatment recommendations. Safran et al. (1998) found support for this in their primary care study using an instrument called the Primary Care Assessment Survey, which included an 8-item subscale for trust (shown to have excellent psychometric properties). They found that adherence was rated at 43.1% among patients with trust scores in the 95th percentile, compared with an adherence rate of only 17.5% in patients with trust scores in the 5th percentile.

Another outcome trajectory of mistrust in a physician is its negative impact on patient satisfaction with their doctor. The Safran et al. study mentioned above found that patients with trust scores in the 95th percentile were approximately five times more likely to express full satisfaction with their primary care doctor than those with median levels of trust (87.5% versus 18.4%, $p < 0.001$). Bachinger et al. (2009) similarly found a significant positive correlation ($r = 0.64$, $p < 0.01$) between scores on a trust scale and satisfaction with the treating physician in a sample (n = 201) of internal medicine patients attending an outpatient clinic. However, caution needs to be exercised in the interpretation of these cross-sectional studies in terms of direction of findings. It is conceivable that satisfaction with (care provided by) a physician leads to

the development of trust in him/her as an experiential phenomenon, rather than trust in the physician being responsible for the reported satisfaction in him/her. However, a study by Thom et al. (1999) sheds some light on this conundrum. The authors found that *base-line trust* predicted satisfaction (as well as treatment adherence and staying the with same physician) six months later, even after adjusting for *base-line satisfaction*, but *base-line satisfaction* did not predict *subsequent satisfaction* unless there was an adjustment for base-line trust.

Other important outcome trajectories associated with mistrust in physicians are reduced utilization of health care services, less continuity of care with greater likelihood to change physicians, more disputes with the physician, lower perceived effectiveness of care, and worse self-reported health (Mechanic & Schlesinger 1996; Thom et al. 1999; Pearson & Raeke 2000; Hall et al. 2001; Thom et al. 2004; O'Malley et al. 2004). As with other outcome trajectories discussed above, these are potentially both contributors to, as well as consequences of, physician mistrust. For instance, if a patient has little contact with health services or is regularly changing physicians, there is less time and opportunity to develop (experiential) trust in the physician. Conversely, if a patient has significantly low levels of expectant, social or experiential trust in health services, they are less likely to engage and utilize these services, or remain with a given physician. Similarly, while disputes with a doctor may contribute to a lowering of trust in him/her, already existing mistrust is likely to provoke disputes.

Mistrust in doctors is likely to have particularly damaging trajectories for people with schizophrenia, though there is a dearth of studies specifically examining trust in physicians for people with this illness. Without successful treatment, people with schizophrenia are less likely to be able to lead productive and rewarding lives, and more likely to have clinically significant levels of distress and higher risk of completed suicide. As described in the studies above there appears to be a correlation between trust in a doctor and medication adherence. Therefore, the presence of mistrust by a patient with schizophrenia in his/her treating doctor (whether this be the family physician, psychiatrist or other medical specialist) is likely to be associated with poorer medical adherence and poor clinical outcomes. These reduced clinical outcomes are likely to translate into poorer levels of functioning in social, academic, occupational, and interpersonal domains, as well as poorer self-care, with downward social drift and a less productive life. People with schizophrenia may have unique barriers to developing trust in their doctor in addition to the various generic factors described earlier. These include: the presence of persecutory auditory hallucinations (sometimes even "commanding" the patient not to believe or trust the doctor, and other people); persecutory delusions; and the need, on occasions, for an involuntary legal status with associated assertive administration of intramuscular medication and inpatient admission. To the best of the candidate's knowledge there has been no research demonstrating a successful intervention which has been shown through valid measures to have improved the level of trust between a patient and his/her physician. Therefore, there is need for studies to evaluate this important area.

Implications for public policy

Although, as described above, there are specific 'illness factors' (e.g. paranoid delusions and hallucinations) in people with schizophrenia, influencing levels of trust in doctors and others, the broader erosion of trust in medical doctors has broad implications for risk communication policies and programs.

The risk communication process involves at least two stakeholders - those communicating the risk and those who are the intended or desired recipients of this communication. A core potential barrier in the risk communication process is mistrust. People with schizophrenia and in other vulnerable groups, and the public more broadly, do not invest equal levels of trust in all health information sources. Trust is particularly important at the time of a pandemic influenza outbreak, especially if the causative virus is hypervirulent with a high case fatality rate, because there may be different risk messages being disseminated from difference sources. The public is likely to respond to the recommendations from the source they view as the most credible and trustworthy. Given the gradual erosion of public trust in medical doctors (especially 'social' trust described above) increasingly more subgroups of patients and citizens are becoming sceptical, and even dismissive, of doctors' health communications. In light of this, it seems that a pragmatic aspect of policy would include a non-physician in the communication of public messaging. A possible appropriate choice could be the state's chief scientist or an academic with a special interest and expertise in the area of influenza outbreaks. However, as described earlier, in addition to social trust is trust in a

given individual. If a particular communicator, regardless of his or her background or profession, has delivered incorrect information in the past, it is likely there will be trust issues in the future. This is especially likely to be true if, as described earlier, there are high levels of uncertainty about what the best course of action during the pandemic is, and precise estimates of risk are not possible. Trust is likely to be compromised if the risk assessment and management processes are not open and transparent, and the public senses some kind of hidden agenda.

Other potential barriers to effective risk communication, working in concert with or amplifying mistrust, include: overuse of technical jargon and scientific terminology; optimistic bias (discussed in chapter two) where individuals have an unbalanced view that the influenza and its consequences will affect other people but not themselves; the communicated message does not engage peoples' specific concerns and real life issues; media hyperbole and rating-seeking distorts messages from credible sources; socio-demographic issues such as language/cultural difference, illiteracy, poverty, marginalization and social disconnectivity, paucity of infrastructure required for communication.

A key study providing useful insights into optimal public policy regarding the risk communication process was conducted by Gray et al. (2012) targeting the 2009 pandemic influenza. The researchers collected qualitative data on community responses to key health messages from the New Zealand Ministry of Health. The sample (n = 80) contained participants from groups that the Ministry of Health identified as vulnerable to the H1N1 virus. These included

people with chronic medical conditions (including diabetes and coronary heart disease), pregnant women, children, and two ethnic groups - Pacific Peoples and Maori. Thematic analysis of data suggested several core characteristics of successful risk communication. Trust, honesty and transparency were found to be very important to the respondents. They indicated that they wanted to be given "the truth" even if it were bad news, and that they wanted it delivered by people they trusted. Consistent with other research (Rubin et al. 2009) participants conveyed their preference for simple, practical advice and recommendations on how to protect themselves and their family from the threat of the pandemic, such as hand washing and social distancing. Other research has shown that people who receive minimal or no information on protective measures that could adopted, not only don't feel empowered but experience a sense of helplessness and frustration (Janssen et al. 2006). Gray et al. (2012) found that responses from all of the vulnerable groups endorsed the value of community based risk management and information dissemination. Responses suggested that trust and engagement in the swine flu campaign had been enhanced by health authorities (District Health Board) actually going out into the community, engaging with citizens and providing them with information and involving them in the planning process. It was also seen as important by respondents that information dissemination was through community mechanisms, such as social and family networks, regular community forums and meetings, health centres and church groups. Other research has also found that community participation, and trust in emergency event planners, increases community preparedness, willingness to take

protective actions, risk acceptance and enhanced communication (Paton 2008).

Other potentially important factors guiding public policy on risk communication (and which may enhance trust) include: ascertaining what risk information people, especially those in vulnerable subgroups like schizophrenia, think is important and want to know; identifying and responding to emotional dimensions of risk perception, with an empathic approach, rather than giving out 'just facts'; explaining risk in different ways; acknowledging uncertainty; shaping the style, including the language used, of the risk communication message to the particular target audience; conveying the 'human' aspects of the risk information not just statistical facts; ensuring that the communication process is bi-directional i.e. from experts and health authorities to the community but also vice versa (Food and Agriculture Organization of the United Nations 1998).

A framework of public health policy strategies to mitigate the negative impact of a pandemic influenza on people with schizophrenia or in other vulnerable groups, informed by these broader issues as well as the thesis research project findings, is shown in Table 7.1.

Table 7.1 Framework: mitigating pandemic influenza risk for vulnerable groups

BETWEEN PANDEMICS
Global surveillance   • Collaboration with WHO in ***international network of surveillance*** of pandemic risk by monitoring for emergence of ***novel viruses*** with potential for rapid human-to-human transmission   • Ongoing virology research including into optimal vaccination and antiviral medication
Influenza education and Response Planning   • Implementation of education package on influenza (both seasonal and pandemic): includes focus on ***symptom profiles*** and ***protective measures***, especially importance of hand washing and vaccination; addresses risk benefit issues, including misconceptions about contracting influenza from killed vaccines   • Response planning: listens to, identifies, and responds to, concerns of vulnerable group representatives, and, if feasible, incorporates their suggestions into policy; use of empathic approach / appropriate language; identifies and promotes key role for GPs; considers possible level of *complacency* in the community about magnitude of threat associated with future pandemics such as possible bird flu with very high case fatality rates, and provides community awareness education to address this
Addressing unhealthy lifestyle behaviours   • Promote / protect universal access to healthcare systems   • Targeted educational programmes on healthy lifestyle: include schools and mental health centres; public messaging on posters in public places, and on television, radio, and the Internet   • Fiscal policy to reduce sale of tobacco and alcohol (e.g. increased taxation) and to promote healthy foods and exercise (e.g. reduced taxation on advertising low-fat, low-sugar, low-salt foods)   • Implementation of environmental measures - "clean air" legislation; restriction of outdoor smoking and/or alcohol advertising that targets low SES neighbourhoods; restriction of fast-food outlets   • Government funded 'packages' facilitating access to health-promoting resources such as gymnasiums, swimming pools, weight loss programs, quit programmes (cigarettes)   • Development of 'healthy living' groups - both inpatient and community health settings   • Stress management programs
Improved management / prevention of chronic medical disorders   • Better integration of mental health and physical health services - collaborative and longitudinal approach   • Provision of physical examination rooms and medical equipment at community mental health centres   • Employment of general practitioners, nurse practitioners and dieticians at community mental health centres to monitor and help improve physical health of patients with a mental illness   • Colleges to make it mandatory for psychiatrist to attend regular update courses on general medicine as part of their continuing professional development requirements for registration   • Conduct regular surveys of mental health staff assessing knowledge and attitudinal factors regarding physical health care of patients   • Software programmes to provide a prompting system for when relevant investigations (e.g. blood tests for lipids / glucose levels, renal function, liver function) for monitoring physical health status, are required   • Provision of written information on relevant physical health issues for patients, carers, and families through community mental health centres
Information sources and trust   • Consider television and community posters for public messaging about influenza outbreaks   • Fund programmes for the purchase of an electronic devices (e.g. computer, smart phone or tablet to enable Internet access) and training to use it, to financially compromised individuals with a significant mental illness or disability   • Develop integrated community health programmes which utilize electronic health resources and are linked with treating clinicians   • Fund research exploring issues of trust in physicians and strategies to improve this

Table 7.1 Framework: mitigating pandemic influenza risk for vulnerable groups (continued)

DURING PANDEMIC
Alert phase

• Support overseas efforts to control source (of novel virus outbreak)
• Stock-pile vaccinations and anti-viral medication - making provision for vulnerable groups (e.g. people with a mental illness)
• Community engagement by local public health planners or delegates, with vulnerable groups, to discuss, in advance, pandemic influenza response; communication to be characterized by:
   ▪ open and transparent discussion on nature and current trajectory of influenza outbreak, including delivery of bad news or uncertainty
   ▪ inclusion of simple practical recommendations on protective actions
   ▪ empathic approach identifying and responding to emotional aspects of perceived risk
   ▪ bi-directional flow of ideas

Delay phase
• Reduce number of travellers to and from high risk overseas area(s) • Screen at borders to detect infected (or high risk) travellers and quarantine if necessary
Contain phase

• Meeting with local health officials to discuss implementation of protective strategies
   ▪ emphasize importance of hand washing
   ▪ supply alcohol-based anti-septic gels (especially to people with low income)
   ▪ involve carers and families
   ▪ encourage contact with general practitioner

Protect / Sustain / Control phases
• Collaboration between mental health services and general medical services in providing regular monitoring of members of vulnerable group including: progress with protective behaviours (including whether vaccine is available), updates on new information about current pandemic, coping capacity and strategies • Provision of psychological support (if necessary) when self isolation at home required • Funding and administration of vaccination when available, including overcoming transport barriers • Early detection and treatment of influenza and its complications if present (encourage links with GP)
Recovery phase
• Remain vigilant for further waves of pandemic • Monitor impact of pandemic on mental state of patient • Provide support and manage any residual anxiety, post-trauma syndromes, or bereavement issues • Review efficacy, strengths and weaknesses of current planning and response preparedness policies and modify / improve these policies based on findings

7.7 Future research

The thesis study was an initial broad-based research project exploring pandemic influenza risk perception and protective behaviours in people with schizophrenia. Further research steps, arising from this study, could include:

▪ conducting a cross-sectional study in people with schizophrenia, to gather data on how participants view new viral threats such as H7N9 (at the time of writing there have been very recent reports of laboratory-confirmed newly emergent H7N9 respiratory illness associated with deaths in China)

• further studies on health information sources for people with schizophrenia that focus on subtypes of sources (e.g. type of magazine: scientific versus popular; doctor: general practitioner versus specialist) and the specific health information being elicited

▪ further exploration of factors which may be associated with trusting, or not trusting, a given information source; this may be particularly helpful with respect to electronic devices used for accessing the Internet such as 'smart phones', 'tablets' and computers, as they are likely to become increasingly more popular, intuitive, interactive, convenient, and technically refined; in addition, research evaluating strategies to improve trust in doctors, with a view to improving doctor-patient relationships and achieving better health outcomes is a worthwhile endeavour

- further exploration of perceived risk and reported willingness to take protective actions in the event of a highly pathogenic H5N1 pandemic, given that outbreaks have occurred in many countries around the world with a mortality rate of approximately 60%; these research data are likely to be of assistance in preparedness and response planning; in light of the substantive lethality of the H5N1 viral strain compared with H1N109, it is possible that, with appropriate dissemination of information to the public, findings of future studies assessing risk perception and willingness to adopt protective measures may be at variance to those of the present study

- research with data collection at two time points - prior to and following the winter season - to assess the correlation between a reported intention to receive a vaccination for seasonal influenza and the actual behaviour of having a vaccination, in people with schizophrenia (such studies have been performed in the general population)

- an interesting and rich area for further research is a deeper exploration of the role of affect in people with schizophrenia both as component of risk perception and as a predictor for intended and actual carrying out of health protective behaviour; the findings in the thesis study are not conclusive but suggest affective factors may play an important role in decision making in people with schizophrenia with respect to intentions to adopt protective measures; predicted affective response of fear in the event of contracting

H1N109 was associated with a fifteen-fold increased likelihood of reported willingness to increase hand washing

7.8 Final conclusions

The thesis began with a literature review, which demonstrated that people with schizophrenia are a potentially vulnerable group to influenza, especially during a pandemic. This vulnerability arises from several key factors including: significant medical comorbidity; increased prevalence of smoking, obesity and excess alcohol consumption, compared with the general population; side effects of psychotropic medication; and poor access to, and engagement, of health services. Risks of adverse clinical outcomes from influenza (and pneumonia) are likely to be further heightened during an influenza pandemic by little or no natural immunity to a novel virus, and health systems being stretched to the limit of their capacity, exacerbating the poor health care access issues experienced by people with schizophrenia. Australia's response plan (AHMPPI) for a pandemic influenza, reflecting WHO global strategies, identifies and emphasizes the need for timely communication of accurate and up-to-date health information during a pandemic and for attempts to reduce the spread of the influenza virus. It has emerged from the thesis research project that there are differences between people with schizophrenia attending mental health care settings, and the general public, in the ways they obtain health information. People with schizophrenia are less likely to access a doctor and the Internet to obtain information on health matters, and are less likely to trust

a doctor. People with schizophrenia appear to share the same level of perceived risk from the H1N109 influenza pandemic as people attending a general practice and report being generally willing to carry out protective measures including vaccination, increased hand washing, isolating themselves, and wearing a face mask, if advised to by government health authorities. However, they appear to be less likely to be willing to receive a vaccination and to isolate themselves compared with the general public. Perceived barriers to undertaking protective behaviours have been identified in the thesis study, and assistance in overcoming these is likely to improve the uptake of protective measures in the event of a future pandemic influenza.

People with schizophrenia in the thesis study were found to have significant differences in socio-demographic characteristics compared with the broader population, including being more likely to be unemployed, less well educated, living alone, and having a lower household annual income. These factors are known to be associated with an increased likelihood of unhealthy lifestyle behaviours, with risk implications for people with schizophrenia, as well as for other vulnerable groups. There is a need and obligation for public policy to address these disparities, enabling greater equity in our communities, with improved social and health outcomes.

Medical practitioners were found in the thesis survey to be the most trusted and most frequently identified source of health information, for both people with schizophrenia and the broader population. In addition, they were viewed as

playing a key role in protecting against and managing an established influenza illness, by patients with schizophrenia. Despite this, there has been erosion in trust in medical clinicians over recent decades. Further research needs to be carried out to explore ways to rebuild trust, as a core element of a healthy and effective doctor-patient relationship.

It is possible that the low virulence of H1N109 may have induced a level of complacency in the community with respect to pandemic influenza. In order to mitigate the risk of future influenza pandemics, public health policy and planning needs to comprise: ongoing global surveillance (for the emergence of novel viruses with the potential for rapid human to human transmission); targeted influenza education strategies; response planning involving key stake holders including health providers, and consumers, including representatives from vulnerable groups such as those with a mental illness; addressing unhealthy lifestyle; and improved management and prevention of chronic disorders; broadening medical education about mental illnesses, including its significant impact on physical health and engagement in public health campaigns.

Finally, the thesis study and its findings provide a stimulus for future research aimed at further evaluating strategies to mitigate the risks for people with schizophrenia, and other vulnerable groups, in the event of another, perhaps more threatening, pandemic influenza in the 21st century, such as a highly pathogenic avian influenza.

References

Ajzen I (1985) From intentions to actions. In Kuhl J, Beckman J (eds) Action
        control from cognition to behaviour. Springer-Verlag, New York

Akan H, Gurol Y, Izbirak G et al. (2010) Knowledge and attitudes of university
        students toward pandemic influenza: a cross-sectional study from
        Turkey. BMC Public Health 10:413

Akiskal HS, Albert KA, Alexander JK et al. (1999) *The Merck Manual.*
        Whitehouse Station, New Jersey: Merck Research Laboratories

Aledort JE, Lurie N, Wasserman J, Bozzette SA (2007) Non-pharmaceutical
        public health Intervention for pandemic influenza: an evaluation of
        the evidence base. *BMC Public Health* 7:208

Allison DB, Casey DE (2001) Antipsychotic-induced weight gain: a review
        of the literature. Journal of Clinical Psychiatry 62(suppl 7):22-31

Allison DB, Newcomer JW, Dunn AL (2009) Obesity among those with mental
        disorders: a National Institute of Mental Health meeting report.
        American Journal of Preventive Medicine 36:341-350

Almirall J, Gonzalez CA, Balanzo X, Bolibar I (1999) Proportion of community
        acquired pneumonia cases attributable to tobacco smoking. Chest
        116:375-379

Altman S, Jackson T (1991) Health Care in Australia: Lesson from Down
        Under. Health Affairs 10(3):129-146

Ananth J (1984) Physical illness and psychiatric disorders. Comprehensive
        Psychiatry 25:586-593

Anderson JG (2004) Consumers of e-health: Patterns of use and barriers. Social Science Computer Review 22:242-248

Anderson KM, Odell PM, Wilson PW, Kannel WB (1991) Cardiovascular disease risk profiles. American Heart Journal 121:293-298

Andrews G, Slade T (2001) Interpreting scores on the Kessler Psychological Distress Scale. Australian and New Zealand Journal of Public Health 2001. 25(6): 494-497

Aro AR, Vartti AM, Schreck M et al. (2009) Willingness to Take Travel-Related Health Risks - A Study among Finnish Tourists in Asia during the Avian Influenza Outbreak. International Journal of Behavioural Medicine 16:68-73

Askarian M, Khazaeipour Z, McLaws M (2009) Influenza vaccination uptake among students and clinical staff of a university in Iran. International Journal of Infectious Diseases 13:476-482

Australian Bureau of Statistics. Education and Work, Australia, May 2009. Catalogue no. 6227.0. Australian Bureau of Statistics, Canberra

Australian Government, Department of Health. Pandemic Influenza. Protecting yourself and others, 7 November 2012 [cited 20 September 2014]. Available at URL: http://www.health.gov.au/fluandyou

Australian Government, Department of Health. Lifestyle Risk Factors, last updated 7 February 2011 [cited 23 July 2014]. Available at URL: http://www.health.gov.au/internet/publications/publishing.nsf/ Content/womens-health-policy-toc~womens-health-policy-experiences~womens-health-policy-experiences-lifestylerisk

Australian Government, Department of Health and Ageing. Archived
Pandemic (H1N1) Influenza 2009 update bulletin 2 June 2009
[Cited 19 February 2011]. Available at URL: http://www.flupandemic.
gov.au/internet/panflu/publishing.nsf/Content/ H1N1%202009-1

Australian Government, Department of Health and Aging. Australian Health
Management Plan for Pandemic Influenza, 2009 [cited 24 July
2009]. Available at URL: http://www.health.gov.au/internet/panflu/
publishing.nsf/Content/ahmppi-2009-l~ahmppi-2009-l-p1~ahmppi-
2009 -l-p1a~ahmppi-2009-l-p1a.5

Australian Government, Department of Health and Aging. Pandemic Influenza,
History of Pandemics, 2009 [cited 28 May 2011]. Available at
URL: http://www.flupandemic.gov.au/internet/panflu/publishing.nsf/
Content/history-1

Australian Government, Medicare Australia, Annual Report 2008-9
Canberra: Medicare Australia, 2009 [cited 10 April 2010]. Available
at URL: http://www.medicareaustralia.gov.au/about/governance/
reports/08-09/stats/index.jsp

Australian Government, National Mental Health Strategy (2005): Australian
Mental Health Outcomes and Classification Network, Kessler-10.
[cited 7 March 2015]. Available at URL: http://amhocn.org/static/files/
assets/2c63fca6/Kessler_10_Manual.pdf

Ayanian JZ, Weissman JS, Scneider EC, Ginsberg JA, Zaslavksy AM (2000)
Unmet health needs of uninsured adults in the United States. Journal
of the American Medical Association 284:2061-2069

Ayanian JZ, Zaslavksy AM, Weissman JS, Scneider EC, Ginsberg JA (2003)
Undiagnosed hypertension and hypercholesterolaemia among
uninsured adults in the Third National Health and Nutrition

Examination Survey. American Journal of Public Health 93:2051-2054

Bachinger S, Kolk A, Smets E (2009) Patients' trust in their physician - Psychometric properties of the Dutch version of the "Wake Forest Physician Trust Scale" 76:126-131

Baldwin JA (1987) Schizophrenia and physical disease: a preliminary analysis of the data from the Oxford Record Linkage Study. In: Baldwin JA, Acheson ED, Graham WJ (eds) Textbook of Medical Record Linkage. Oxford University Press New York, pp. 133-157

Balf G, Stewart TD, Whitehead R et al. (2008) Metabolic Adverse Events in Patients with Mental Illness Treated with Antipsychotics: A Primary Care Perspective Primary Care Companion Journal of Clinical Psychiatry 10:15-24

Bandura A (1994) Social cognitive theory and exercise of control over HIV infection. In DiClemente RJ, Peterson JL (eds) Preventing AIDS: Theories and methods of behavioural interventions, Plenum Press, New York, pp. 25-29

Barbeau EM, Krieger N, Soobader M-J (2004) Working class matters: socioeconomic disadvantage, race/ethnicity, gender and smoking in NHIS 2000. American Journal of Public Health 94:269-278

Barennes H, Martinez-Aussel B, Vongphrachanh P et al. (2007) Avian influenza risk perceptions, Laos. Emerging Infectious Diseases 13:1126-1128

Barnes T, Paton C (2001) Do antidepressants improve negative symptoms in schizophrenia? British Medical Journal 342:d3371 doi: 10.1136/bmj. schizophrenia? British Medical Journal 342:d3371

Barr M, Raphael B, Taylor M et al. (2008) Pandemic influenza in Australia: Using telephone surveys to measure perceptions of threat and willingness to comply. BMC Infectious Diseases 8:117

Barret R, Randle J (2008) Hand hygiene practices: nursing students' perceptions. Journal of Clinical Nursing17:1851-1857

Barry JM (2005) The Great Influenza. Penguin Books Ltd, London

Bartsch DA, Shern DL, Feinburg LE et al. (1990) Screening CMHC outpatients for physical illness Hospital and Community Psychiatry 41:786-790

Basile V, De Luca V, Müller D J et al. (2001) Genetic dissection of atypical antipsychotic-induced weight gain: novel preliminary data on the psychogenetic puzzle. Journal of Clinical Psychiatry 62(Supplement 23):45-66

Batki SL, Meszaros ZS, Strutynski K, Dimmock JA, Leontieva L, Ploutz-Snyder R, Canfield K, Drayer RA (2009) Medical comorbidity in patients with schizophrenia and alcohol dependence. 107:139-146

Black W, Nease R, Tosteson A (1995) Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. Journal of the National Cancer Institute 87:720-731

Blake K, Blendon R, Viswanath K (2010) Employment and compliance with pandemic influenza mitigation recommendations. Emerging Infectious Diseases 16:212-218

Bleich S, Blendon R, Adams A (2007) Trust in scientific experts on obesity: implications for awareness and behaviour change. Obesity 15: 2145-2156

Bolon M (2011) Hand hygiene. Infectious Disease Clinics of North America 25:21-43

Boneau CA (1960) The effects of violations of assumptions underlying the *t* test. Psychological Bulletin 57:49-64

Bonhoeffer K (1912) The psychoses associated with acute infections and general internal diseases. In Handbook of Psychiatry, Leipzig

Braceland FJ, Meduna LJ and Vaichulis JA (1945) Delayed action of insulin in schizophrenia. American Journal of Psychiatry 102:108-110

Brashers DE (2001) Communication and uncertainty management. Journal of Communication 51, 477-497

Brewer NT, Chapman GB, Gibbons FX et al. (2007) Meta-analysis of the relationship between risk perception and health behaviour: The example of vaccination. Health Psychology 26;136-145s

Brown S (1997) Excess mortality of schizophrenia: a meta-analysis. British Journal of Psychiatry 171:502-508

Brown S, Birtwistle J, Roe L, Thompson C (1999) The unhealthy lifestyle of with schizophrenia. Psychological Medicine 29:697-701

Brown S, Inskip H, Barraclough B (2000) Causes of the excess mortality of schizophrenia. British Journal of Psychiatry 177: 212-217

Brug J, Aro AR, Oenema A, de Zwart O et al. (2004) SARS risk perception, knowledge, precautions, and information sources, The Netherlands. Emerging Infectious Diseases 10:1486-1489

Budescu DV, Wallsten TS (1985) Consistency in interpretation of probabilistic phrases. Organizational Behavior and Human Decision Processes 36: 391-405

Bults M, Beaujean D, de Zwart O et al. (2010) Mexican flu: risk perceptions in the general public, precautionary measures and trust in information provided by the government. Nederlands Tijdschrift voor Geneeskunde 154:A1686

Burdette A, Hill T (2008) An examination of processes linking perceived neighborhood disorder and obesity. Social Science and Medicine 67:38-46

Burke AW (1978) Physical disorder among day hospital patients. British Journal of Psychiatry 133:22-27

Burns T, Drake B (2011) Mental health services for people with schizophrenia. In Weinberger DR, Harrison PJ (eds) Schizophrenia, Chapter 30. Blackwell Publishing Ltd, Oxford, pp. 625-643

Cantor-Graae E, Nordstrom LG, McNeil TF (2001) Substance use in schizophrenia: a review of the literature and a study of correlates in Sweden. Schizophrenia Research 49:69-82

Carifo J, Perla R (2007) Ten Common Misunderstandings, Misconceptions, Persistent Myths and Urban Legends about Likert Scales and Likert Response Formats and their Attributes. Journal of Social Sciences 3:106:116

Carney CP, Jones L, Woolson RF (2006) Medical Comorbidity in Women and
Men with Schizophrenia. Journal of General Internal Medicine
21:1133-1137

Casey DE (2005) Metabolic issues and cardiovascular disease in patients with
psychiatric disorders. The American Journal of Medicine 118,
Suppl 2, 15S-22S

Cava MA, Fay KE, Beanlands HJ et al. (2005) Risk Perception and
Compliance With Quarantine During the SARS Outbreak. Journal of
Nursing Scholarship 37:343-347

Centers for Disease Control and Prevention. Influenza Symptoms. September
2010 [Cited 26 September 2010]. Available at URL: http://cdc.gov/flu/
symptoms.htm

Centers for Disease Control and Prevention. Interim Recommendations for
Facemask and Respirator Use to Reduce 2009 Influenza A (H1N1)
Virus Transmission. CDC, 2009 [cited 22 Feb 2011]. Available at
URL: http://www.cdc.gov/h1n1flu/mask.htm

Centers for Disease Control and Prevention. Novel H1N1 Flu Situation
Update. CDC, 2009 [cited 22 Feb 2011]. Available at URL:
http://www.cdc.gov/h1n1flu/updates/072409.htm

Centers for Disease Control and Prevention. People at High Risk of
Developing Flu-Related Complications. November 2012 [cited 11 Nov
2012]. Available at URL: http://www.cdc.gov/flu/about/disease/
high_risk.htm

Centers for Disease Control and Prevention. Preventing Seasonal Flu Illness.
Last updated 1 August 2013 [cited 20 September 2014]. Available at
URL: http://www.cdc.gov/flu/about/qa/preventing.htm

Centers for Disease Control and Prevention. Vaccine Effectiveness – How Well Does the Flu vaccine work? February 2011 [4 October 2011] Available at URL: http://www.cdc.gov/flu/about/qa/vaccineeffect.htm

Chang VW, Christakis NA (2005) Income inequality and weight status in US metropolitan areas. Social Science and Medicine 61:83-96

Chapin J (2001) Self-protective pessimism: optimism bias in reverse. North American Journal of Psychology 3:253-262

Chen Y-H, Lin H-C, Lin H-C (2010) Poor clinical outcomes among pneumonia patients with schizophrenia. Schizophrenia Bulletin 37:1088-1094

Chen C-K, Murray RM (2004) How does drug abuse interact with familial and developmental factors in the aetiology of schizophrenia? In Keshavan MS, Murray RM (eds) Neurodevelopment and Schizophrenia. Cambridge University Press, Cambridge, pp. 248-269

Chor JS, Ngai KL, Goggins WB et al. (2009) Willingness of Hong Kong healthcare workers to accept pre-pandemic influenza vaccination at different WHO alert levels: two questionnaire surveys. British Medical Journal 339:b3391

Christensen H, Griffiths K (2000) The Internet and mental health literacy. Australian and New Zealand Journal of Psychiatry 34:975-979

Chwastiak LA, Rosenheck RA, McEvoy JP, Keefe RS, Swartz MS, Lieberman JA (2006) Interrelationships of psychiatric symptom severity, medical comorbidity, and functioning in schizophrenia. Psychiatric Services 57:1102-1109

Clason DL, Dormody TJ (1994) Analyzing Data Measured by Individual Likert-
Type Items. Journal of Agricultural Education 35:31-35

Cohen J (1969) Statistical power analysis for the behavioral sciences.
Academic Press, New York

Cohen L, Manion L, Morrison K (2000) Research methods in education.
RoutledgeFalmer, London

Collignon P (2010) Swine flu – lessons learnt in Australia. Medical Journal of
Australia 192 (7): 364-365

Collignon PJ, Carnie JA (2006) Infection control and pandemic influenza.
Medical Journal of Australia 185: S54–S57

Connolly M, Kelly C (2005) Lifestyle and physical health in schizophrenia.
Advances in Psychiatric Treatment 11:125-132

Cormac I, Ferriter M, Benning R et al. (2005) Physical health and health risk
factors in a population of long-stay psychiatric patients. Psychiatric
Bulletin 29:18-20

Council for International Organizations of Medical Sciences in collaboration
with the World Health Organization. International Ethical Guidelines
for Biomedical Research involving Human Subjects, 2002. [cited 14
December 2012]. Available at URL: http://www.cioms.ch/publications/
layout guide2002.pdf

Cowling BJ, Ng DMW, Ip DKM et al. (2010) Community Psychological and
Behavioural Responses through the First Wave of the 2009 Influenza
A (H1N1) Pandemic in Hong Kong. Journal of Infectious Diseases
202:867-876

Crowther RE, Marshall M, Bon GR et al. (2001) Helping people with severe mental illness to obtain work: systematic review. British Medical Journal 322:204-208

Cummins S, McKay L, Macintyre S (2005) McDonald's restaurants and neighborhood deprivation in Scotland & England. American Journal of Preventive Medicine 4:308-310

Cutler D, Lleras-Muney A (2010) Understanding differences in health behaviors by education. Journal of Health Economics 29:1-28

Dart J, Gallois C, Yellowlees P (2008) Community health information sources - a survey in three disparate communities. Australian Health Review 32:186-196

Davis WD (1965) Physical illness in psychiatric outpatients. British Journal of Psychiatry 1965 111:27-33

De Hert MA, van Winkel R, Van Eyck D et al. (2006) Prevalence of the metabolic syndrome in patients with schizophrenia treated with antipsychotic medication. Schizophrenia Research 83: 87-93

De Noouer J, Lechner L, De Vries H (2001) Help-seeking behaviour for cancer symptoms: perceptions of patients and general practitioners. Psychooncology 10:469-478

DeSalvo KB, Bloser N, Reynolds K, He J, Munter P (2005) Mortality Prediction with a Single General Self-Rated Health Question A Meta-analysis. Journal of General Internal Medicine 20:267-275

De Wandel, Maes L, Labeau S et al. (2010) Behavioural determinants of hand hygiene compliance in intensive care units. American Journal of Critical Care 19: 230-239

De Zwart O, Veldhuijzen IK, Richardus JH et al. (2010) Monitoring of risk perceptions and correlates of precautionary behaviour related to human avian influenza during 2006 - 2007 in the Netherlands: results of seven consecutive surveys. BMC Infectious Diseases 10:11

De Zwart O, Veldhuijzen IK, Elam G (2007) Avian Influenza Risk Perception Europe and Asia. Emerging Infectious Diseases 13(2):290-293

Dickert BA, Ezekiel E, Grady C (2002) Paying Research Subjects: An Analysis of Current Policies. Annals of Internal Medicine 136:368-373

Diefenbach M, Weinstein ND, O'Reilly, J (1993) Scales for assessing perceptions of personal risk susceptibility. Health Education Research 8:181-192

Di Giuseppe G, Abbate R, Albano L, Marinelli P, Angelillo IF (2008) A survey of knowledge, attitudes and practices towards avian influenza in an adult population of Italy. BMC Infectious Diseases 8:36

Dolan G, Iredale R, Williams R, Ameen J (2004) Consumer use of the Internet for health information: A survey of primary care patients. International Journal of Consumer Studies 28:147-153

Doody MM, Sigurdson AS, Kampa et al. (2003) Randomized Trial of Financial Incentives and Delivery Methods for Improving Response to a Mailed Questionnaire. American Journal of Epidemiology 157: 643-651

Druss BG, Bradford WD, Rosenheck RA, Krumholz HM (2001) Quality of medical care and excess mortality in older patients with mental disorders. Archives of General Psychiatry 58:565-572

Dunn JR (2010) Health Behavior vs the Stress of Low Socioeconomic Status and Health Outcomes. Journal of American Medical Association 303:1199-1200

Eastwood K, Durrheim DN, Jones A, Butler M (2010) Acceptance of pandemic (H1N1) 2000 influenza vaccination by the Australian public. Medical Journal of Australia 192:33-36

Eastwood K, Durrheim DN, Butler et al. (2010) Responses to Pandemic (H1N1) 2009, Australia. Emerging Infectious Diseases 16(8):1211-1216

Eastwood MR, Mindham RHS, Tenneut TG (1970) The physical status of psychiatric emergencies. British Journal of Psychiatry 116:545-560

Engl J, Laimer M, Niederwanger A et al. (2005) Olanzapine impairs glycogen synthesis and insulin signalling in L6 skeletal muscle cells. Molecular Psychiatry10:1089-96

Esterberg ML, Compton MT (2005) Smoking behavior in persons with a schizophrenia spectrum disorder: a qualitative investigation of the transtheoretical model. Social Science & Medicine 61:293-303

European Centre for Disease Prevention and Control. Definition of a Pandemic, 2012 [cited March 2013]. Available at URL: http:www. ecdc. Europa.eu/en/healthtopics/pandemic_preparedness/basic_ facts/pages/ definition_of_pandemic.aspx

Everts RJ, Murdoch DR, Chambers ST et al. (2000) Nosocomial pneumonia in adult general medical and surgical patients at Christchurch Hospital. New Zealand Medical Journal 113: 221-24

Fabrega H (1990) The concept of somatization as a cultural and historical product of Western medicine. Psychosomatic Medicine 52:653-672

Farah MJ, Shera DM, Savage JH, Betancourt L, Giannetta JM, Brodsky NL, Malmud EK, Hurt H (2006) Childhood poverty: specific associations with neurocognitive development. Brain Research 1110:166-174

Farr BM, Bartlett CL, Wadsworth J, Miller DL (2000) Risk factors for community acquired pneumonia diagnosed upon hospital admission. British Thoracic Society Pneumonia Study Group. Respiratory Medicine 94:954-963

Fasina OF, Bisschop SP, Ibironke AA et al. (2009) Avian Influenza Risk Perception among Poultry Workers, Nigeria. Emerging Infectious Diseases 15:616-617

Feemster K, Prasad P, Smith M et al. (2011) Employee designation and health care worker support of an influenza vaccine mandate at a large paediatric tertiary care hospital. Vaccine 29:1762-1769

Felker B, Yazel JJ, Short D (1996) Mortality and Medical Comorbidity Among Psychiatric Patients: A Review. Psychiatric Services 47:1356-1363

Fernandez-Sola J, Junque A, Estruch R, Monforte R, Torres A, Urbano-Marquez A (1995) High alcohol intake as a risk and prognostic factor for community-acquired pneumonia. Archives of Internal Medicine155:1649-54

Ferng YH, Wong-McLoughlin J, Barret A, Currie L, Larson E (2011) Barriers to mask wearing for influenza-like illnesses among urban Hispanic households. Public Health Nursing 28:13-23

Fielding R, Lam WW, Ho EY, Lam H et al. (2005) Avian influenza risk perception, Hong Kong. Emerging Infectious Diseases 11:677-82

Finklea JF, Hasselblad V, Riggan WB, Nelson WC, Hammer DI, Newill VA (1971) Cigarette smoking and hemagglutination inhibition response to influenza after natural disease and immunization. American Review of Respiratory Disease 104:368-376

Finucane ML, Alhakami A, Slovic P et al. (2000) The affect heuristic in judgements of risks and benefits. Journal of Behavioural Decision Making 13:1-17

Fischhoff B, De Bruin WB (1999) Fifty–fifty = 50%? Journal of Behavioral Decision Making 12:149-163

Fishbein M, Ajzen I (1975) Beliefs, attitudes, intention and behaviour: An introduction to theory and research. Addison Wesley, Reading (Massachusetts)

Fleischhacker WW, Cetkovich-Bakmas M, De Hert et al. (2008) Comorbid somatic illnesses in patients with severe mental disorders: clinical, policy, and research challenges. Journal of Clinical Psychiatry 69: 514-519

Floyd D, Prentice-Dunn S, Rogers RW (2000) A Meta-Analysis of Research on Protection Motivation Theory. Journal of Applied Social Psychology 30:407-429

Folsom S, Jeste D (2002) Schizophrenia in homeless persons: a systematic review of the literature. Acta Psychiatrica Scandanavica 105:404-413

Food and Agriculture Organization of the United Nations (1998) Strategies for
Effective Risk Communication [cited 23 July 2014]. Available at URL:
http://www.fao.org/docrep/005/x1271e/X1271E05.htm

Forchuk C, Norman R, Malla A et al. (2002) Schizophrenia and the motivation
for smoking. Perspectives in Psychiatric Care 38(2):41-9

Forsythe RJ, Ilk CR, Bard J et al. (1977) Primary medical care in psychiatry.
Current Psychiatric Therapy 17:91-97

Freedman R, Adler LE, Bickford P et al. (1994) Schizophrenia and nicotinic
receptors. Harvard Review of Psychiatry 2:179-192

Gaglia MA, Cook RL, Kraemer KL et al. (2008) Patient knowledge and
attitudes about avian influenza in an internal medicine clinic. Public
Health 122: 462-470

Gallego, G. Australia's Government response to H1N1 Influenza. Health
Policy Monitor, Oct 2009. [Cited 19 Feb, 2011]. Available at
URL: http://www.hpm.org/survey/au/a14/2

Gargano LM, Painter JE, Sales JM (2011) Seasonal and 2009 H1N1 influenza
vaccine uptake, predictors of vaccination, and self-reported
barriers to vaccination among secondary school teachers and staff.
Human Vaccine 7(1):89-95

Gelder M, Harrison P, Cowen P (2006) Schizophrenia and schizophrenia-like
disorders. In Shorter Oxford Textbook of Psychiatry, Chapter 12.
Oxford University Press, Oxford, pp. 329-377

Gigerenzer G. (2007) Gut Feelings: The Intelligence of the Unconscious.
Viking Press, New York

Glass GV, Peckham PD, Sanders JR (1972) Consequences of failure to meet assumptions underlying the analyses of variance and covariance. Review of Educational Research 42:237-288

Godin G, Vezina-Im LA, Naccache H (2010) Determinants of influenza vaccination among healthcare workers. Infection Control and Hospital Epidemiology 31:689-693

Goldman LS (1999) Medical illness in patients with schizophrenia. Journal of Clinical Psychiatry 60:10-15

Goodwin JM, Goodwin JS, Kellner R (1979) Psychiatric symptoms in disliked medical patients. Journal of the American Medical Association 241:1117-1120

Goodwin R, Haque S, Neto F, Myers LB (2009) Initial psychological responses to Influenza A, H1N1 ("Swine flu"). BMC Infectious Diseases 9:166

Goold SD (2002) Trust, Distrust and Trustworthiness. Journal of General Internal Medicine 17:79-81

Government of Western Australia, Department of Health. About Human Swine Influenza (H1N1) 2009. [Cited 26 June 2011]. Available at URL: http://www.health.wa.gov.au/ flu/swine_flu/index.cfm

Gray L, MacDonald C, Mackie B et al. (2012) Community responses to communication campaigns for influenza A (H1N1): a focus group study. BMC Public Health 2012, 12:205

Grayson ML, Melvani S, Druce J et al. (2009) Efficacy of soap and water and alcohol-based hand-rub preparations against live H1N1 influenza virus on the hands of human volunteers. Clinical Infectious Diseases 43:285-291

Gregg L, Barrowclough C, Haddock G (2007) Reasons for increased substance use in psychosis. Clinical Psychology Review 27:494-510

Hall MA, Dugan E, Zheng B, Mishra AK (2001) Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? Milbank Quarterly 79:613-639

Hall RW, Garner ER, Stickney SK, et al. (1980) Physical illness manifesting as psychiatric disease: analysis of a state hospital inpatient population. Archives of General Psychiatry 37:989-995

Halloran ME, Ferguson NM, Eubank S et al. (2008) Modeling targeted layered containment of an influenza pandemic in the United States. Proceedings of the National Academy of Sciences of the United States of America 105(12):4639-4644

Harris AE (1988) Physical disease and schizophrenia. Schizophrenia Bulletin 14:85-96

Harris EC, Barraclough B (1998) Excess mortality of mental disorder. British Journal of Psychiatry 173:11-53

Helms B, Dorval S, St. Laurent P, Winter M (2010) Improving hand hygiene compliance: A multidisciplinary approach. American Journal of Infection Control 38:572-574

Herran A, Garcia-Unzueta MT, Amado JA, et al. (2001) Effects of long-term treatment with antipsychotics on serum leptin levels. British Journal of Psychiatry 179:59-62

Herridge LF (1960) Physical disorders in psychiatric illness. Lancet 2: 949-951

Hesse BW, Nelson DE, Kreps GL et al. (2005) Trust and sources of health
information. Archives of Internal Medicine 165:2618-2624

Hind CR (1990) Pulmonary complications of intravenous drug misuse.
1. Epidemiology and non-infective complications. Thorax 1990;
45:891.

Hjorth P, Davidsen AS, Kilian R, Skrubbeltrang C (2014) A systematic review
of controlled interventions to reduce overweight and obesity in
people with schizophrenia. Acta Psychiatrica Scandinavica
130(4):279-289

Hoorens V (1994) Unrealistic optimism in health and safety risks. In
Rutter DR, Quine L (eds) Social Psychology and Health: European
Perspectives. Avebury Press, Aldershot (UK), pp. 153-174

Ibuka Y, Chapman GB, Meyers LA et al. (2010) The dynamics of risk
perceptions and precautionary behaviour in response to 2009 (H1N1)
pandemic influenza. BMC Infectious Diseases 10:296

Imber J (2008) The Decline of Moral Authority in American Medicine.
Princeton University Press, Princeton

Institute of Medicine, Committee on the Consequences of Uninsurance.
Insuring America's health: principles and recommendations, 2004
[cited 18 June 2014]. Available from URL: http://www.iom.edu/
~/media/Files /Report%20Files/2004/Insuring-Americas-Health-
Principles-and-Recommendations/Uninsured6EnglishFINAL.pdf

Jablensky A, Kirkbride JB, Jones PB (2011) Schizophrenia: the
epidemiological horizon. In Weinberger DR, Harrison PJ (eds)
Schizophrenia, Chapter 10. Blackwell Publishing Ltd, Oxford, pp.
185-225

Jacobson PD, Lantz P, Warner K, Wasserman J, Pollack H, Ahlstrom A (2001) Combating Teen Smoking. Research and Policy Strategies. University of Michigan Press, Ann Arbor (Michigan)

Jakobsson U (2004) Statistical Presentation and Analysis of Ordinal Data in Nursing Research. Scandinavian Journal of Caring Sciences 18:437-440

Jamieson S (2004) Likert scales: how to (ab)use them. Medical Education 38:1212-1218

Janseen AP, Tardif RR, Landry SR, Warner JE (2006) Why Tell Me Now. The Public and healthcare Providers Weigh in on Pandemic Influenza Messages. Journal of Health Management and Practice 12:388-394

Jefferson T, Del Mar C, Dooley L et al. (2010) Physical interventions to interrupt or reduce the spread of respiratory viruses. Cochrane Database of Systematic 2010; (1): CD006207

Jefferson T, Foxlee R, Del Mar C et al. (2008) Physical interventions to interrupt or reduce the spread of respiratory viruses: systematic review BMJ; 336:77

Jeste DV, Gladsjo JA, Lindamer LA, Lacro JP (1996) Medical comorbidity in Schizophrenia. Schizophrenia Bulletin 22: 413-430

John AP, Koloth R, Dragovic M, Lim SCB (2009) Prevalence of metabolic syndrome among Australians with severe mental illness. Medical Journal of Australia 190:176-179

Johnson DW (1968) Evaluation of routine physical examination in psychiatric cases. Practitioner 200:686-691

Johnson RA, Hoffman JP (2000) Adolescent cigarette smoking in U.S. racial/ethnic subgroups: findings from the National Education Longitudinal Study. Journal of Health and Social Behaviour 41:392–407

Jones JH, Salathe M (2009) Early Assessment of Anxiety and Behavioural Response to Novel Swine-Origin Influenza A (H1N1). PloS One 4(12):e8032

Jones P, Seoane L, Deichmann R, Kantrow C (2011) Differences and Similarities in the Practice of Medicine Between Australia and the United States if America: Challenges and Opportunities for The University of Queensland and the Ochsner Clinical School. The Ochsner Journal 11:253-258

Kao AC, Green DC, Zaslavsky AM, Koplan JP, Cleary PD (1998) The relationship between method of physician payment and patient trust. Journal of the American Medical Association 280:1708-1714

Kasanin J (1926) The blood sugar curve in mental disease. The Schizophrenia (dementia praecox) Groups. Archives of Neurological Psychiatr*y* 16:414-419

Karasu TB, Waltzman SA, Lindenmayer JP et al. (1980) The medical care of patients with psychiatric illness. Hospital and Community Psychiatry 31:463-472

Karpel JP (2013) Overview of pulmonary disease in injection drug users. [cited 20 March 2015]. Available at URL: http://www.uptodate. com /contents/ overview - of-pulmonary-disease-in-injection-drug-users

Katon WJ (2003) Clinical and health services relationships between major

depression, depressive symptoms, and general medical illness. Biological Psychiatry 54:216-226

Kaufman J, Davis J, Krause V (2008) Influenza immunisation of doctors at an Australian Tertiary Hospital: immunisation rate and factors contributing to uptake. Communicable Diseases Intelligence 32: 443-448

Keltner N, Grant JS (2006) Smoke, smoke, smoke that cigarette. Perspectives in Psychiatric Care 42(4):256-61

Kessler RC, Andrews G, Colpe LJ et al. (2002) Short screening scales to monitor population prevalences and trends in non-specific psychological distress. Psychological Medicine 32:959-976

Knapp T (1990) Treating Ordinal Scales as Interval Scales: An Attempt to Resolve the Controversy. Nursing Research 39:121-3

Kohn R, Saxina S, Levav I, Saraceno B (2004) The treatment gap in mental health care. Bulletin of the World Health Organization 82:858-866

Koran LM, Sox HC, Morton KI et al. (1989) Medical evaluation of psychiatric patients: results in a state mental system. Archives of General Psychiatry 46:711-740

Koranyi EK (1972) Physical health and illness in a psychiatric outpatient department population. Canadian Psychiatric Association Journal 17 (suppl.):109-116

Koranyi EK (1979) Morbidity and rate of undiagnosed physical illnesses in a psychiatric clinic population. Archives of General Psychiatry 36: 414-419

Krueger PM, Chang V (2008) Being poor and coping with stress: health behaviors and the risk of death. American Journal of Public Health 98:889–896

Kuzon WM Jr, Urbanchek MG, McCabe S (1996) The seven deadly sins of statistical analysis. Annals of Plastic Surgery 37:265-272

LaJoie AS, Ridner SL (2009) Health information and health risk behaviours in a sample of college students. Journal of the Kentucky Medical Association 107:58-63

Lambert TJR, Velakoulis D, Pantelis C (2003) Medical comorbidity in schizophrenia. Medical Journal of Australia 178:S67-S70

Lantz PM, House JS, Mero RP, Williams DR (2005) Stress, life events, and socioeconomic disparities in health: results from the Americans' Changing Lives Study. Journal of Health and Social Behaviour 46:274-288

Larsen TK, Melle I, Ausestad E et al. (2006) Substance abuse in first-episode non-affective psychosis. Schizophrenia Research 88:55-62

Larson E (2004) A tool to assess barriers to adherence to hand hygiene guideline. American Journal of Infection Control 32:48-51s

Last J (2001) A dictionary of epidemiology (4th Edition). Oxford University Press, New York

Lau JTF, Griffiths S, Choi KC, Lin C (2010) Prevalence of preventive behaviours and associated factors during early phase of the H1N1 influenza epidemic. American Journal of Infectious Control s38(5): 374-380

Lau JTF, Griffiths S, Choi KC, Tsui HY (2009) Widespread public misconception in the early phase of the H1N1 influenza epidemic. Journal of Infection 59:122**e**127

Lau JTF, Kim JH, Tsui HY et al. (2007) Anticipated and current preventative behaviours in response to an anticipated human-to-human H5N1 epidemic in Hong Kong Chinese general population. BMC Infectious Diseases 7(18)

Lau JTF, Yang X, Tsui H, Kim JH (2003) Monitoring community psychological responses to the SARS epidemic in Hong Kong: From day 10 to day 62. Journal of Epidemiology and Community Health 57:864-870

Lawrence D, Holman CDJ, Jablensky AV (2001) Preventable Physical Illness in People with Mental Illness. Perth: The University of Western Australia

Lawrence D, Kisely S (2010) Inequality of healthcare provision for people with severe mental illness. Journal of Psychopharmacology 24(11):61-68

Layte R, Whelan CT (2009) Explaining social class inequalities in smoking: the role of education, self- efficacy, and deprivation. European Sociological Review 25:399-410

Lazzarino A, Yiengprugsawan V, Suebsman S, Steptoe A, Sleigh A (2014) The associations between unhealthy behaviours, mental stress, and low socio-economic status in an international comparison of representative samples from Thailand and England. Globalization and Health 10:10

Leas L, McCabe M (2007) Health behaviours among individuals with schizophrenia and depression. Journal of Health Psychology 12: 563- 579

Lehman AF, Lieberman JA, Dixon LB (2004) Practice Guideline for the
Treatment of Patients with Schizophrenia. American Journal of
Psychiatry 161 (Suppl. 2):1-56

Leucht S, Burkard T, Henderson J (2007) Physical illness and schizophrenia:
a review of the literature. Acta Psychiatriaca Scandanavica 116:
317-333

Leung GM, Lam T-H, Ho L-M et al. (2003) The impact of community
psychological responses on outbreak control for severe acute
respiratory syndrome in Hong Kong. Journal of Epidemiology and
Community Health 57:857-863

Levander S, Eberhard J, Lindstrom E (2007) Nicotine dependence among
psychotic patients, and its correlates. Acta Psychiatrica
Scandanavica 435:27-32Leventhal H, Nerenz DR, Steele DJ (1984)

Leventhal H, Nerenz DR, Steele DJ (1984) Illness representations and coping
with health threats. Handbook of Psychology and Health 4:219-252

Levy J (2014) U.S. Uninsured Rate Continues to Fall. Gallup Wellbeing. [cited
18 June 2014]. Available at URL: http://www.gallup.com/poll/
167798/ uninsured-rate-continues-fall.aspx

Liao Q, Lam WW, Jiang C Q et al. (2009) Avian Influenza Risk Perception and
Live Poultry Purchase in Guangzhou, China, 2006. Risk Analysis
29(3):416-424

Likert R (1932) A technique for the measurement of attitudes. Archives of
Psychology 140:1-55

Lima BR, Pai S (1987) Concurrent medical and psychiatric disorders among

schizophrenic and neurotic outpatients. Community Mental Health Journal 23:30-39

Link BG (2008) Epidemiological sociology and the social shaping of population health. Journal of Health and Social Behaviour 49:367-384

Linville PW, Fischer SW (1991) Preferences for separating and combining events. Journal of Personality and Social Psychology 60:5-23

Lipkus I, Samsa G, Rimer, B (2001) General performance on a scale among highly educated samples. Medical Decision Making, 21, 37-44

Lipper S, Werman DS (1977) Schizophrenia and Intercurrent Physical Illness: A Critical Review of the Literature Comprehensive Psychiatry 18:11-22

Lipsky BA, Boyko EJ, Inui TS, Koepsell TD (1986) Risk factors for acquiring pneumococcal infections. Archives of Internal Medicine 146: 2179- 2185

Lo JY, Tsang TH, Leung YH, et al. (2005) Respiratory infections during SARS outbreak, Hong Kong. Emerging Infectious Diseases 11:1738-1741

Looi JCL, Raphael B (2007) Reflections on therapy in the era of the Internet. Australasian Psychiatry 15:334-337

Lutfey K, Freese J (2005) Towards some fundamentals of fundamental causality: socioeconomic status and health in the routine clinic visit for diabetes. American Journal of Sociology 110:1326-1372

MacCallum R, Zhang S, Preacher K, Rucker D (2002) On the Practice of

Dichotomization of Quantitative Variables. Psychological Methods 7:19-40

MacIntyre CR, Cauchemez S, Dwyer DE et al. (2009) Face mask use and control of respiratory virus transmission in households. Emerging Infectious Diseases 15:233-241

Maddock J (2004) The relationship between obesity and the prevalence of fast-food restaurants: state-level analysis. American Journal of Health Promotion 19:137-143

Maguire GP, Granville-Grossman KC (1968) Physical Illness in psychiatric patients. British Journal of Psychiatry 115:1365-1269

Maguire PA, Reay RE, Looi JCL et al. (2011) Neither the internist nor the Internet: use of and trust in health information sources in people with schizophrenia. Australian and New Zealand Journal of Psychiatry 45:489-497

Mallia P, Johnston S L (2007) Influenza infection and COPD. International Journal of COPD 2:55–64

Maltezou H, Maragos A, Katerelos P et al. (2008) Influenza vaccination acceptance among health-care workers: A nationwide survey. Vaccine 26:1408-1410

Maricle RA, Hoffman WF, Bloom JD, et al. (1987) The prevalence and significance of medical illness among chronically mentally ill outpatients. Community Mental Health Journal 23(2):81-90

Marder SR, Essock SM, Miller AM (2004) Physical Health Monitoring of Patients With Schizophrenia. American Journal of Psychiatry 161:1334-1349

Margolese HC, Malchy L, Negrete JC, et al. (2004) Drug and alcohol use among patients with schizophrenia and related psychoses: levels and consequences. Schizophrenia Research 67:157-166

Marshall HS (1949) Incidence of physical disorders among psychiatric inpatients: a study of 175 cases. British Medical Journal 2:468-470

McCorrick AK, Manderscheid RW, Bertolucci DE et al. (1986) Chronic medical problems in the chronically mentally ill. Hospital and Community Psychiatry s 37:289-291

McCreadie RG, Scottish Schizophrenia Lifestyle Group (2003) Diet, smoking and cardiovascular risk in people with schizophrenia: descriptive study. British Journal of Psychiatry 183:534-539

McEvoy JP, Meyer JM, Goff DC et al. (2005) Prevalence of the metabolic syndrome in patients with schizophrenia: baseline results from the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) schizophrenia trial and comparison with national estimates from NHANES III. Schizophrenia Research 80:19-32

McGorry P, Killachey E, Yung A (2007) Early intervention in psychotic disorders: detection and treatment of the first episode and the critical early stages. Medical Journal of Australia 187:S8-S10

McIntyre RS, Mancini DA, Basile VS (2001) Mechanisms of antipsychotic-induced weight gain. Journal of Clinical Psychiatry 62 (Supplement 23):23-29

Mechanic D (1996) Changing medical organization and the erosion of trust. Milbank Quarterly 74:171-189

Mechanic D, Schlesinger (1996) The impact of managed care on patients'

trust in medical care and their physicians. Journal of the American Medical Association 275:1693-1697

Mental Health Consumer Outcomes Task Force (2000) Mental Health Rights and Responsibilities. Australian Government Printing Service, Canberra

Millstein S, Halpern-Felsher BL (2002) Judgements about risk and perceived invulnerability in adolescents and young adults. Journal of Research on Adolescence 12:399-422

Millstein S, Halpern-Felsher BL (2002) Perceptions of Risk and Vulnerability. Journal of Adolescent Health S 31:10-27

Mokdad AH, Marks JS, Stroup DF, Gerberding JL (2004) Actual causes of death in the United States 2000. Journal of the American Medical Association 291:1238-1245

Molina P, Happel K, Zhang P, Kolls J, Nelson S (2011) Focus on: Alcohol and the Immune System. Alcohol Research and Health [cited 11 Nov 2012]. Available at URL: http://pubs.niaaa.nih.gov/publications/arh40/97-108.htm

Monteleone P, Fabrazzo M, Torterella A et al. (2002) Pronounced early increase in circulating leptin predicts a lower weight gain during clozapine treatment. Journal of Clinical Psychopharmacology 22: 424-426

Moore SM, Rosenthal DA (1996) Young people assess their risk of sexually transmissible diseases. Psychology and Health 11:345-355

Morgan OW, Bramley A, Fowlkes A, Freedman DS, Taylor TH et al. (2010) Morbid Obesity as a Risk Factor for Hospitalization and Death Due to

2009 Pandemic Influenza A(H1N1) Disease. PLoS ONE 5(3): e9694. doi:10.1371/journal.pone.0009694

Morgan VA, Waterreus A, Jablensky A, Mackinnon A, McGrath JJ, Carr V, Bush R, Castle D, Cohen M, Harvey C, Galletly C, Stain HJ, Neil AL, McGorry P, Hocking B, Shal S, Saw S (2012) People living with psychotic illness in 2010: The second Australian national survey of psychosis. Australian and New Zealand Journal of Psychiatry 46:735-752

Munk-Jorgensen P, Mors P, Mortensen PB, Ewald H (2000) The schizophrenic patient in the somatic hospital. Acta Psychiatrica Scandinavica 102:96-99

Murin S, Bilello K (2005) Respiratory tract infections: Another reason not to smoke. Cleveland Clinic Journal of Medicine 72:916-920

Murugan AT, Sharma G (2008) Obesity and respiratory diseases. Chronic Respiratory Disease 5:233-242

Musa D, Schulz R, Harris R et al. (2009) Trust in the health care system and the use of preventive health services by older black and white adults. American Journal of Public Health 99:1293-1299

Nasrallah HA, Meyer JM, Goff DC, et al. (2006) Low rates of treatment for hypertension, dyslipidemia and diabetes in schizophrenia: data from the CATIE schizophrenia trial sample at baseline. Schizophrenia Research 86:15-22

National Centre for Immunisation Research and Surveillance. Fact Sheet Influenza. Influenza vaccines for Australians: Information for immunisation providers, 2011. [cited 10 Nov 2012]. Available at

URL: http://www.ncirs.edu.au/immunisation/fact-sheets/influenza-fact-sheet.pdf

National Health and Medical Research Council. Influenza, 2008. [cited March 2013]. Available at URL:http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/Handbook-influenza#14

National Vascular Disease Prevention Alliance (2009) Evidence-based practical guidelines for the assessment of absolute cardiovascular disease risk. [cited 7 March 2015]. Available at URL: http://www.heartfoundation.org.au/SiteCollectionDocuments/guidelines-Absolute-risk.pdf

Nazarko L (2009) Potential pitfalls in adherence to hand washing in the community. British Journal of Community Nursing 14:64-68

Newcomer JW (2005) Second-generation (atypical) antipsychotics and metabolic effects: a comprehensive literature review. CNS Drugs 19 (Suppl. 1):1-93

Newcomer JW, Hennekens CH (2007) Severe mental illness and risk of cardiovascular disease. Journal of the American Medical Association 298:1794-1796

Newcomer JW, Leucht S (2011) Metabolic adverse effects associated with antipsychotic medications. In Weinberger DR, Harrison PJ (eds) Schizophrenia, Chapter 28. Blackwell Publishing Ltd, Oxford, pp. 577-597

Ng DM, Jeffery RW (2003) Relationships between perceived stress and health behaviors in a sample of working adults. Health Psychology 22:638-642

Norman G (2010) Likert scales, level of measurement and the "laws" of statistics. Advances in Health Science Education 15:625-632

Nuno M, Chowell G, Gumel AB (2007) Assessing the role of basic control measures, antivirals and vaccine in curtailing pandemic influenza: scenarios for the US, UK and the Netherlands. Journal of the Royal Society Interface 4:505-21

Olincy A, Young DA, Freedman R (1997) Increased levels of the nicotine metabolite cotinine in schizophrenic smokers compared to other smokers. Biological Psychiatry 42:1-5

O'Malley AS, Sheppard VB, Schwartz M, Mandelblatt J (2004) The role of trust in use of preventive services among low-income among African-American women. Preventive Medicine 38:777-785

Osby U, Correia N, Brandt L, Ekbom A, Sparen P (2000) Time trends in schizophrenia mortality in Stockholm County, Sweden: cohort study. British Medical Journal 321(7259):483-484

Pallant J (2007) SPSS Survival Manual. Allen & Unwin, Sydney

Pampel F (2005) Diffusion, cohort change, and social patterns of smoking. Social Science Research 34:117–139

Pampel F, Krueger P, Denney J (2010) Socioeconomic Disparities in Health Behaviors. Annual Review of Sociology 36:349-370

Parsons T (1951) The social system. Illinois Free Press, Glencoe (Illinois)

Paton D (2008) Modeling societal resilience to pandemic hazards in Auckland. GNS Science Report, 13:23

Peabody FW (1927) The care of the patient. Journal of the American Medical
Association 88:877-882

Pearson E (1931) The analysis of variance in the case of non-normal
variation. Biometrika 23:114–133

Pearson SD, Raeke LH (2000) Patients' trust in physicians: many theories,
few measures, and little data. Journal of General Internal
Medicine15:509-513

Peltz R, Avisar-Shohat G, Bar-Dayan Y (2007) Difference in public emotions,
interest, sense of knowledge and compliance between the affected
area and the nationwide general population during the first phase of a
bird flu outbreak in Israel. Journal of Infection 55:545-50

Petrie K, Jago L, Devcich D (2007) The role of illness perceptions in patients
with medical conditions. Current Opinion in Psychiatry 20:163-167

Philips RJ (1934) Physical Disorder in 164 consecutive admissions to a
mental hospital: the incidence and significance. British Medical
Journal 2:363-366

Pittet D (2001) Compliance with hand disinfection and its impact on
hospital-acquired infections. Journal of Hospital Infection 48:S40-46

Potter CW (2001) A history of influenza. Journal of Applied Microbiology 91:
572-579

Pratt LA, Brody DJ (2010) Depression and smoking in the US household
population aged 20 and over, 2005-2008. NCHS data brief, no 34.
Hyattsville, Maryland: National Centre for Health Statistics

Prentice KJ, Gold JM, Carpenter WT (2005) Optimistic Bias in the Perception

of Personal Risk: Patterns in Schizophrenia. American Journal of Psychiatry 162:507-512

Pyle GF (1986) The Diffusion of Influenza: Patterns and Paradigms. Rowan and Littlefield, New Jersey

Rains SA (2007) Perceptions of Traditional Information Sources and Use of the World Wide Web to Seek Health Information: Findings From the Health Information National Trends Survey. Journal of Health Communication 12:667-680

Reavley NJ, Jorm AF, Cvetkovski S, Mackinnon AJ (2011) National Depression and Anxiety Indices for Australia. Australian and New Zealand Journal of Psychiatry 45:780-787

Regier DA, Farmer ME, Rae DS et al. (1990) Comorbidity of mental disorders with alcohol and other drug abuse: Results from the Epidemiologic Catchment Area (ECA) study. Journal of the American Medical Association 264:2511-2518

Reynolds GP, Zhang Z, Zhang X (2003) Polymorphism of the promoter region of the serotonin 5-HT 2c receptor gene and clozapine-induced weight gain. American Journal of Psychiatry 160:677-679

Roca RP, Breakey WR, Fischer PJ (1987) Medical care of chronic psychiatric outpatients. Hospital and Community Psychiatry 38:741-745

Rogers RW (1975) A protection motivation theory of fear appeals and attitude change. Journal of Psychology 91:93-114

Rogot E, Murray JL (1980) Smoking and causes of death among U.S. veterans: 16 years of observation. Public Health Report 95:213-222

Rose A, Peters N, Shea J, Armstrong K (2004) Development and Testing of the Health Care System. Journal of General Internal Medicine 19:57-63

Rosenstock IM (1974) Historical origins of the health belief model. In Becker MH (ed) The Health Belief Model and personal health behaviour. Thorofare, New Jersy, pp. 1-8

Rubin GJ, Amlot R, Page L, Wessely S (2009) Public perceptions, anxiety and behavior change in relation to the swine flu outbreak: cross-sectional telephone survey. British Medical Journal 339:b2691

Safran DG, Taira DA, Rogers WH et al. (1998) Linking primary care performance to outcomes of care. Journal of Family Practice 47: 213-220

Sagud M, Mihaljevic-Peles A, Muck-Seler D et al. (2009) Smoking and schizophrenia. Psychiatria Danubina 21:371-375

Saha S, Chant D, McGrath J (2007) A Systematic Review of Mortality in Schizophrenia. Is the Differential Mortality Gap Worsening Over Time? Archives of General Psychiatry 64(10):1123-1131

Saitz R, Ghali WA, Moskowitz MA (1997) The impact of alcohol-related diagnoses on pneumonia outcomes. Arch Intern Med 157:1446-52

Schmidt W, De Lint J (1972) Causes of death of alcoholics. Quarterly Journal of Studies on Alcohol 33:171-85

Seale H, Heywood AE, McLaws M-L et al. (2010) Why do I need it? I am not at risk! Public perceptions towards the pandemic (H1N1) 2009 BMC Infectious Diseases 10:99

Setbon M, Raude J (2010) Factors in vaccination intention against the
pandemic influenza A/H1N1. European Journal of Public Health
20:490-494

Sharpe M (1998) Psychiatry in relation to other areas of medicine. In
Johnstone EC, Freeman CP, Zealley AK (eds) Companion to

Psychiatric Studies, Chapter 27. Churchill Livingstone, Edinburgh,
pp. 785-805

Shroufi A, Copping J, Musonda P et al. (2009) Influenza vaccine uptake
among staff in care homes in Nottinghamshire: A random cluster
sample survey Public Health 123:645-649

Siahpush M, Borland R, Taylor J, Singh GK, Ansari Z, Serraglio A (2006) The
association of smoking with perception of income inequality, relative
material well-being, and social capital. Social Science and Medicine
63:2801-2812

Singer R (2001) The first mortality follow-up study: the 1841 Report of William
Farr (physician) on the mortality of lunatics. Journal of Insurance
Medicine 33: 298-309

Slovic P (2000) The Perception of Risk. Cromwell Press, Trowbridge

Slovic P, Fischhoff B, Lichtenstein S (1982) "Why Study Risk Perception?"
Risk Analysis 2(2):83-93

Stahl SM, Mignon L, Meyer JM (2009) Which comes first: atypical
antipsychotic treatment or cardiometabolic risk? Acta Psychiatrica
Scandanivica 119:171-179

Story A (2013) Recreational drugs and lung disease. [cited 20 March 2015].

Available at URL: http://www.thoracic.org.au/imagesdb/
wysiwyg/tueswf20700alistairstory.pdf

Sundararaman R (2009) The U.S. Mental Health Delivery System
Infrastructure: A Primer. Congressional Research Service, 2009.
[cited 18 June 2014]. Available at URL:http://www.fas.org/sgp/
crs/misc/R40536.pdf

Tam DKP, Lee S, Lee SS (2007) Impact of SARS on avian influenza
preparedness in healthcare workers. Infection 35:320-325

Tang CSK, Wong C-Y (2004) Factors influencing the wearing of face masks to
prevent the severe respiratory syndrome among Chinese in Hong
Kong. Preventive Medicine 39:119

Taubenberger JK (2006) The Origin and Virulence of the 1918 "Spanish"
Influenza Virus. Proceedings of the Philosophy Society 150:86-112

Thistlethwaite JE, Leeder SR, Kidd MR et al. (2008) Addressing general
practice workforce shortages: policy options. Medical Journal of
Australia 189:118-121

Thom DH, Hall MA, Pawlson G (2004) Measuring patients' trust in
physicians when assessing quality of care. Health Affairs 23:
124-132

Thom DH, Ribisl KM, Stewart AL, Duke DA, Stanford Trust Study Physicians
(1999) Further validation and reliability testing of the Trust in
Physician Scale. Medical Care 37:510-517

Thomas S, Fayter D, Misso K, Ogilvie D, Petticrew M et al. (2008) Population
tobacco control interventions and their effects on social inequalities in
smoking: systematic review. Tobacco Control 17:230-237

Tsoi DT, Porwal, Webster AC Interventions for smoking cessation and
reduction in individuals with schizophrenia. Cochrane Database of
Systematic Reviews 2013 Feb 28;2:CD007253. doi: 10.1002/
14651858.CD007253.pub3. Review.

Tsuang MT, Perkins K, Simpson JC (1983) Physical disease in schizophrenia
and affective disorder. Journal of Clinical Psychiatry 44: 42-46

Ulrich CM, Danis M, Koziol D, Garrett-Mayer E, Hubbard R, Grady C (2005)
Does it Pay to Pay? A Randomized Trial of Prepaid Financial
Incentives and Lottery Incentives in Surveys of Nonphysician
Healthcare Professionals. Nursing Research, 54(3):178–183

United States Department of Health and Human Services. Agency for
Healthcare Research and Quality. Chapter 9. Access to Health Care:
National Healthcare Quality Report, 2011. [cited 18 June 2014].
Available at URL: http://ahrq.gov/research/findings/nhqrdr/nhqr11/
chapter9.html

United States Department of Health and Human Services (1989) Reducing the
health consequences of smoking: 25 years of progress—a report of
the Surgeon General. Rockville, MD: Centers for Disease Control

Valdez R, Narayan V, Geiss L, engelgau MM (1999) Impact of Diabetes
Mellitus on Mortality Associated with Pneumonia and Influenza
Among Non-Hispanic Black and White US Adults. American Journal
of Public Health 89:1715-1721

van der Pligt J (1994) Unrealistic optimism in health and safety risks. In
Rutter DR, Quine L (eds) Social Psychology and Health: European
Perspectives. Avebury Press, Aldershot (UK)

van der Velde FW, Hooykaas C, van der Pligt J (1992). Risk perceptions

and behaviour: pessimism, realism, and optimism about AIDS-related behaviour. Psychology and Health 6:23-38

Vestri HS, Maianu L, Moellering DR et al. (2007) Atypical antipsychotic drugs directly impair insulin action in adipocytes: effects on glucose transport, lipogenesis and antilipolysis. Neuropsychopharmacology 32, 765-772

Virkkunen M, Wahlbeck K, Rissanen A et al. (2002) Decrease of energy expenditure causes weight increase in olanzapine treatment - a case study. Pharmacopsychiatry 35:124-126

von Hausswolff-Juhlin Y, Bjartveit M, Lindstrom E, Jones P (2009) Schizophrenia and physical health problems. Acta Psychiatrica Scandanivica 119 (Suppl. 438):15-21

Waldron I (2000) Trends in gender differences in mortality – Relationships to changing gender differences in behaviour and other causal factors. In Annandale E and Hunt K (eds) Gender Inequalities in Health, Chapter 6. Buckingham (UK), Open University Press, pp.150-182

Walter-Ryan WG, Alarcon RD, Meadows DT et al. (1987) Toward a profile of medically ill psychiatric patients. Southern Medical Journal 80: 822-826

Warner K (2005) Tobacco policy in the United States: lessons for the obesity epidemic. In Mechanic D, Rogut LB, Colby DC (eds) Policy Challenges in Modern Health Care. New Brunswick (New Jersey), Rutgers University Press, pp. 99-114

Weinstein ND (1980) Unrealistic optimism about future life events. Journal of Personality and Social Psychology 39:806-820

Weinstein ND (1984) Why it won't happen to me: perceptions of risk factors and susceptibility. Health Psychology 3:431-457

Weinstein ND (1987) Unrealistic optimism about susceptibility to health problems: conclusions from a community-wide sample. Journal of Behavioural Medicine 10:481-500

Weinstein ND (1989) Optimistic biases about personal risks. Science 246: 1232-1233

Weinstein ND, Kwitel A, McCaul KD et al. (2007) Risk Perceptions: Assessment and Relationship to Influenza Vaccination. Health Psychology 26:146-151

Wewiorski NJ, Fabian ES (2004) Association between demographic and diagnostic factors and employment outcomes for people with psychiatric disabilities: A synthesis of recent research. Mental Health Services Research 6:9-21

Wilper A, Woolhandler S, Lasser K, McCormick D, Bor D, Himmelstein D (2009) Health Insurance and Mortality in US Adults. American Journal of Public Health 99:2289-2295

Woloshin S, Schwartz LM, Byram S, Fischhoff et al. (2000) A new scale for assessing perceptions of chance. Medical Decision Making 20: 298-307

Wong EM, Cheng MM, Lo SK (2010) Teachers' Risk Perception and Needs in Addressing Infectious Disease Outbreak. Journal of School Nursing 26:398-406

World Health Organization (2009) Pandemic influenza preparedness and response: a WHO guidance document. WHO Press, Geneva

World Health Organization (2009) WHO Guidelines on Hand Hygiene in
        Health Care [cited 23 July 2014]. Available at URL: http://whqlibdoc.
        who.int/publications/2009/9789241597906_eng.pdf

World Health Organization (2011) Programs and Projects. Global Alert and
        Response. Cumulative Number of Confirmed Human Cases of Avian
        Influenza A (H5N1) Reported to WHO [2 August 2011].
        Available at URL: http://www. who.int/csr/disease/avian_influenza/
        country/cases_table_2011_06_22/en/index.htmls

Wray R, Becker SM Henderson N et al. (2008) Communicating with the public
        about emerging health threats: lessons from the pre-event message
        development project. American Journal of Public Health 98:
        2214-2222

Zhang P, Bagby GJ, Happel KI, Raasch CE, Nelson S (2008) Alcohol abuse,
        immunosuppression, and pulmonary infection. Current Drug Abuse
        Reviews 1:56-67

Zwar N (2010) Family medicine in the USA. Australian Family Physician
        39:360-361

Appendix 1

Publication:

Neither the internist nor the Internet: use of and trust in health information sources by people with schizophrenia

Neither the internist nor the Internet: use of and trust in health information sources by people with schizophrenia

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Objective: The aim of this study was to explore health information sources accessed by people with schizophrenia and the level of trust invested in them.
Method: A cross-sectional survey was performed comparing the responses of 71 adults with schizophrenia (recruited from both community and inpatient settings) with 238 general practice attendees on their use of television, radio, the Internet, newspapers, magazines, family and friends, and doctor to obtain information on health matters, and their levels of trust in these sources.
Results: People with schizophrenia most commonly reported using a doctor, family and friends, and television to obtain information on health matters. However, compared with general practice attendees, they gained less health information from doctors and the Internet, and had less trust in doctors. Within-group analysis revealed that in people with schizophrenia: living alone increased the likelihood of obtaining health information from television; a higher level of education increased the odds of trusting the Internet as a health information source; a higher estimated household income was associated with an increased likelihood of trusting newspapers; and women with schizophrenia were considerably more likely than men with schizophrenia to trust family and friends as providers of health information. For both groups, there were significant positive correlations between the amount of health information obtained from a given information source and the level of trust invested in it.
Conclusions: There are significant differences in the reported utilization and trust of health information sources between people with schizophrenia and attendees at general practice settings. Those with schizophrenia are less likely to trust and obtain information from a doctor, and less likely to access the Internet. Further research is required to explore this disparity. This is critical given the high rates of comorbid physical illness and reduced longevity in people suffering from schizophrenia.
Key words: health information sources, trust.

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Ex veritate salus: Out of truth/understanding comes health. Motto of the Royal Australian and New Zealand College of Psychiatrists

Access to, and utilization of, relevant information sources is essential in order to make informed decisions about health threats. However, there is a dearth of research exploring how people with schizophrenia obtain information on health matters. There are also high rates of comorbid physical illness and reduced longevity in people with schizophrenia [1–9]. A 13-year follow-up study [1] found a standardized mortality ratio of 298 for people diagnosed with schizophrenia. Most of the excess deaths were accounted for by recognized medical disorders, especially cardiovascular disease. People with schizophrenia also have poor access to primary health care and exhibit poor adherence to general medical treatment [1,7,9]. Numerous studies have examined lifestyle factors as possible contributors to comorbid medical illness and found that, compared with the general population, people with schizophrenia are more likely to consume a diet higher in fat and lower in fibre, take less exercise, smoke cigarettes, be overweight, and have harmful levels of illicit substance use [2,10–13]. Therefore, there is a critical need for people with schizophrenia to receive evidence-based and appropriately communicated health information.

In this initial study we aimed to broadly explore the amount of health information people with schizophrenia obtain from various sources and the level of trust they invest in those sources, compared with people attending a general practice setting who did not report a diagnosis of schizophrenia.

Methods

Participants

Participants in this cross-sectional survey (n = 309) were part of a larger study (n = 382) we carried out examining a range of health issues, including pandemic influenza risk perception. This paper reports on results related to participants' use of, and trust in, health information sources. Volunteers between the ages of 18 and 65 (inclusive) were recruited from mental health settings in the Australian Capital Territory (ACT) and 13 general practices (purposively selected on the basis of geographic diversity of location in the ACT) over a four month period (July to October 2009). The mental health settings included two inpatient psychiatric units, four community mental health centres, two private psychiatric practices and a residential psychiatric rehabilitation unit. Flyers and information brochures describing the study were placed in foyer areas and waiting rooms, and patients were invited to participate in the study. Those who were not capable of providing informed consent or not having the capacity to complete the questionnaire were excluded from the study.

The study discussed in this paper involved two groups of participants: (i) people attending mental health settings who had been diagnosed with schizophrenia (SCZ) by their treating psychiatrist (who was contacted by the researchers), and (ii) people attending a general practice (GP) setting. No participants in the GP group reported suffering from schizophrenia.

There were 238 participants in the GP group. Out of a total of 144 participants recruited from the mental health settings, 71 had received a diagnosis of schizophrenia (50 from community mental health centres, 12 from one of the psychiatric inpatient units and nine from the rehabilitation unit). Socio-demographic characteristics are shown in Table 1.

A naturalistic sample of patients with mental illness was sought for which an adequate comparator could be found. People with schizophrenia not linked with health services were seen as being less likely to be accurately diagnosed and more difficult to recruit. General practice attendees were viewed as a reasonable comparator group: accessible and likely to respond to the invitation to be involved in our study.

Participants in the SCZ group all had regular contact with a psychiatrist or psychiatric registrar. In the hospital inpatient unit this was at least several times a week, and not less frequently than third monthly in the community mental health centres and rehabilitation centre. The general practices were predominantly small urban group practices. Ascertainment of the precise nature and frequency of services accessed by participants in either group would require a further survey and this was seen as beyond the scope and focus of the current study, but could be the subject of future research.

Ethics approval was obtained from the Australian National University, ACT Health, and Calvary-ACT Health Human Research Ethics Committees.

Measures

Participants were invited to complete a questionnaire which included items on how much information on health matters they obtained from various sources including doctors, the Internet, television, radio, magazines, newspapers, and family and friends. They responded on a 5-point Likert scale. Possible responses included: 1 = none, 2 = a little, 3 = a moderate amount, 4 = a lot and 5 = an extreme amount. They were then asked to rate their level of trust in each of these sources as providers of health information, using the same scale. These

Table 1. Socio-demographic characteristics with statistical differences between SCZ and GP groups			
	SCZ (n = 71)	**GP (n = 238)**	**Statistic**
Age			
Mean	36.6	36.1	t = 0.37, p = 0.72
SD	14.0	9.7	
Range	19–62	18–65	
Gender			χ^2 = 28.9, p = 0.00*
Male	70%	34%	
Female	30%	66%	
Highest level of education			χ^2 = 50.7, p = 0.00*
None	11.3%	1.7%	
Year 10 certificate	31.0%	15.1%	
Year 12 certificate	25.4%	20.2%	
TAFE certificate/diploma	23.9%	14.3%	
University degree	8.5%	48.7%	
Estimated yearly household (gross) income ($)			χ^2 = 73.3, p = 0.00*
<20,000	70.1%	19.6%	
20,000–40,000	13.4%	14.0%	
40,000–60,000	10.4%	9.4%	
60,000–80,000	3.0%	14.0%	
>80,000	3.0%	43.0%	
Currently employed	8.3%	91.7%	χ^2 = 50.3, p = 0.00*
Lives alone	33.8%	12.2%	χ^2 = 16.5, p = 0.00*
Children in household	5.6%	43.7%	χ^2 = 33.2, p = 0.00*
Language other than English spoken in household	20.0%	22.5%	χ^2 = 0.1, p = 0.79

*Statistically significant result; SD, standard deviation; SCZ, schizophrenia; GP, general practice.

measures are similar to those employed in other studies examining risk perceptions of outbreaks of respiratory infection, which have used 5-point Likert scales when assessing information sources accessed and levels of confidence in them [14,15].

Statistical analysis

All analyses were carried out using SPSS version 17. Preliminary analyses of the data were performed to ensure that there were no violations of the assumptions for the statistical tests employed. The data were examined for significant differences between the SCZ and GP groups using an independent t-test, chi-square test, Mann-Whitney U test and binary logistic regression. Odds ratios were obtained after Likert responses were dichotomized into either (i) 'none or a little' or (ii) 'a moderate, a lot or an extreme amount' of information obtained from, or trust in, a given source. Ordinal regression was not used because the proportional odds assumption/test of parallel lines was violated. In addition to crude scores, adjusted odds ratios were calculated, controlling for age, gender, socioeconomic status, living alone, children in the household and non-English

language spoken in the home. These variables were considered likely to have an impact on choice of information source used since they were also viewed as potential important predictors of pandemic influenza risk perception and protective behaviours against contracting influenza (in the larger study).

Correlation between amount of information obtained from a given source and the level of trust in it was calculated using Spearman's rho.

Within-group multivariate analyses using logistic regression were performed to explore the relationship between demographic characteristics (as independent/ predictor variables) and a significant amount of information obtained from, or trust invested in, each information source (dependent variables). As with the between-group regression analysis, the dependent variable responses were dichotomized into 'none or a little' versus 'a moderate, a lot or an extreme amount'. The best predictor of amount of use and trust was sought for each information source.

Results

The mean age in the SCZ group was 36.6 years (SD = 14; range = 19–62) and 36.1 years in the GP group

(SD = 9.7; range = 18–65). In the SCZ group 70% of participants were male compared with 34% in the GP group. As might be anticipated there was also a disparity between the two groups in estimated household annual income and highest level of education achieved, with almost 50% of GP attendees reporting attainment of a university degree compared with less than 10% in the SCZ group.

An independent t-test showed no significant difference between the SCZ and GP groups in terms of age but chi-square tests confirmed significant differences for gender distribution, employment status, living alone, estimated household annual income and highest level of education. There was no statistical difference for non-English language spoken in the home. Differences were controlled for as potential confounders in regression analysis.

As shown in Table 2, the most commonly used sources for obtaining a significant amount of information on health matters for participants in the SCZ group were, in rank order, doctor, family and friends, and TV. More than 50% of people in this group reported obtaining at least a moderate amount of information from each of these sources. By comparison, for GP attendees, most health information was derived from, in rank order, a doctor, the Internet, and family and friends. Approximately 60% of participants with schizophrenia reported obtaining at least a moderate amount of information from a doctor compared with about 80% in the case of GP attendees. Only 35.2% of people in the SCZ group reported using the Internet as a significant source of health information compared with 66.5% for GP attendees.

Mann-Whitney U tests (Table 3) indicated significant differences between SCZ and GP groups in the amount of health information obtained from a doctor, the Internet, television and radio. With respect to trust there were significant differences between the two groups only for doctor and the Internet.

As revealed in Table 2, regression analyses indicated that people with schizophrenia were only about a quarter as likely to obtain at least a moderate amount of information from their doctor compared to GP attendees, and less than half as likely to significantly access health information from the Internet. Compared with GP attendees, people with schizophrenia were significantly less likely to trust their doctor (Table 4).

Results of the within-group multivariate regression analyses are shown in Table 5. In the SCZ group: living alone increased almost five-fold the likelihood of obtaining at least a moderate amount of health information from television; a higher level of education made it more than twice as likely that a person with schizophrenia would trust the Internet as a health information source; a higher estimated yearly household income was associated with a greater likelihood of trusting newspapers; and women with schizophrenia were close to seven times more likely to trust family and friends as providers of health information than men with schizophrenia.

In both groups there was a statistically significant positive correlation (Table 6) between the amount of information obtained from a given source and the level of trust invested in it, except for newspaper in the schizophrenia group.

Discussion

Use of health information sources

People with schizophrenia are exposed to health threats arising from both their significant vulnerability to comorbid medical disorders as well as risks and challenges associated with their mental illness. Therefore, the disparity in our study between the SCZ and GP groups in the use of doctors and the Internet as a health information source is of concern.

Table 2. Comparison of SCZ and GP groups in the reporting of at least a moderate amount of information obtained from a given source

	SCZ (%) n = 71	GP (%) n = 238	OR (95%CI)	p	AOR (95%CI)	p
Doctor	59.2	80.7	0.35 (0.2–0.61)	0.00*	0.27 (0.12–0.60)	0.00*
Internet	35.2	66.5	0.27 (0.24–0.72)	0.00*	0.43 (0.22–0.88)	0.02*
Family and friends	53.5	58.4	0.82 (0.48–1.4)	0.47	0.74 (0.37–1.49)	0.41
Television	52.1	34.0	2.11 (1.23–3.61)	0.01*	1.51 (0.78–2.96)	0.23
Radio	37.1	20.6	2.28 (1.3–4.06)	0.01*	1.58 (0.75–3.31)	0.23
Newspaper	19.7	29.1	0.60 (0.31–1.14)	0.12	0.61 (0.27–1.35)	0.22
Magazine	25.4	23.9	1.10 (0.59–1.99)	0.81	1.45 (0.67–3.15)	0.35

*Statistically significant level; SCZ, schizophrenia; GP, general practice; OR, odds ratio; AOR, adjusted odds ratio.

Table 3. Differences between SCZ and GP groups in amount of health information obtained from, and level of trust in, a given source

Mann-Whitney U test		z	r	Mean rank		Median value		p
				Scz	GP	Scz	GP	
Amount of health information								
Doctor	6201.5	−3.548	0.20	123.4	164.4	3	4	0.00*
Internet	5578.5	−4.397	0.25	114.6	165.9	2	3	0.00*
Television	6584.5	−2.980	0.17	181.3	147.2	3	2	0.00*
Radio	6292.0	−3.310	0.19	183.6	145.9	2	2	0.00*
Newspaper	7774.0	−1.032	0.06	145.5	157.2	2	2	0.30
Magazine	8272.0	−0.285	0.02	157.5	154.3	2	2	0.61
Family and friends	8316.0	−0.211	0.01	153.1	155.6	3	3	0.83
Level of trust								
Doctor	5364.5	−5.042	0.29	168.0	111.6	4	4	0.00*
Internet	6226.5	−3.496	0.20	123.7	164.3	2	3	0.00*
Television	7378.5	−1.729	0.10	170.1	150.5	2	2	0.08
Radio	7296.0	−1.839	0.10	171.2	150.2	2	2	0.06
Newspaper	7929.5	−0.830	0.05	147.7	157.2	2	2	0.41
Magazine	7979.5	−0.509	0.03	149.5	155.3	2	2	0.61
Family and friends	7969.0	−0.576	0.03	149.3	156.0	3	3	0.57

*Statistically significant level; Cohen criteria for r values: 0.1, small effect; 0.3, medium effect; 0.5, large effect; SCZ, schizophrenia; GP, general practice.

People suffering from schizophrenia need to be able to receive relevant and optimally communicated health information from their doctor(s). However, significant barriers exist. There is evidence that they may experience difficulty in identifying or communicating a physical (or mental) symptom, on which to seek information. A study of 102 consecutive patients admitted to the acute medical care unit of a psychiatric hospital found that less than a quarter could accurately describe the symptoms of their physical illness [16]. This was particularly true of pain, consistent with evidence from other studies for greater pain tolerance in people with schizophrenia [17–19]. Another important obstacle is a shortage of GPs in some regions [20]. With respect to our study, the ACT has the lowest GP bulk billing rate of any state or territory in Australia as well as a relative shortage of GPs [21]. This is particularly relevant given that a large majority of participants in the SCZ group in our study reported an estimated annual household income of less than $20,000. There is also evidence of inequality with respect to physical health care in people with schizophrenia compared to those without this illness. For example, people with schizophrenia attending a general practice, even though as a group they have been found to be more likely to suffer from hyperlipidemia, are less likely to have a recent record of their cholesterol level or to have received a script for a statin (cholesterol lowering agent) compared to people without

Table 4. Comparison of SCZ and GP groups in the reporting of at least a moderate amount of trust in a given source

	SCZ (%) n = 71	GP (%) n = 238	OR (95%CI)	p	AOR (95%CI)	p
Doctor	77.5	96.2	0.14 (0.06–0.32)	0.00*	0.22 (0.06–0.74)	0.01*
Internet	35.2	56.7	0.42 (0.24–0.72)	0.00*	0.63 (0.32–1.26)	0.13
Family and friends	62.9	67.2	0.83 (0.47–1.44)	0.50	1.02 (0.5–2.08)	0.46
Television	42.3	35.3	1.34 (0.78–2.3)	0.29	1.15 (0.59–2.26)	0.68
Radio	36.6	34.5	1.10 (0.63–1.91)	0.74	1.01 (0.51–2.03)	0.97
Newspaper	35.2	39.9	0.82 (0.47–1.42)	0.48	1.06 (0.64–2.72)	0.87
Magazine	30.0	31.2	0.94 (0.53–1.69)	0.85	1.32 (0.61–2.21)	0.46

*Statistically significant level; SCZ, schizophrenia; GP, general practice; OR, odds ratio; AOR, adjusted odds ratio.

Table 5. Best predictor of a significant amount of use or level of trust for each information source (within-group multivariate regression analysis)

	Use	Exp (B)	p	Trust	Exp (B)	p
SCZ						
Doctor	ns			ns		
Internet	ns			Highest level of education	2.24	0.01
Television	Living alone	4.65	0.01	ns		
Family and friends	ns			Female	6.71	0.02
Radio	ns			ns		
Newspaper	ns			Estimated household income	4.19	0.04
Magazines	ns			ns		
GP						
Doctor	Female	2.51	0.01	ns		
Internet	Highest level of education	1.64	0.00	ns		
Television	Living alone	4.93	0.01	ns		
Family and friends	Non-English language spoken at home	2.62	0.01	ns		
Radio	ns			ns		
Newspaper	Unemployed	2.54	0.01	Highest level of education	1.36	0.02
Magazines	Non-English language spoken at home	2.28	0.02	ns		

Predictor (independent) variables include: age, gender, living alone, employment status, children in the household, highest level of education, estimated annual household income, and non-English language spoken at home; dependent variables include: use, at least a moderate amount of information obtained from a given source, and trust, at least a moderate level of trust in a given source. P values only given for statistically significant predictors; Exp (B), Exponential of regression coefficient B; ns, nil statistically significant (predictors); SCZ, schizophrenia; GP, general practice.

schizophrenia [22]. See Table 7 for a summary of barriers to treatment (a component of which is the provision of health information).

There has been an expansion of the Internet as an accessible, dynamic and interactive information source for mental and physical health issues [26]. Furthermore, the Internet has been promulgated as enhancing mental health literacy and promoting engagement in mental heath programmes,

Table 6. Spearman's correlations between amount of use of a given information source and the corresponding level of trust

	SCZ (n = 71)		GP (n = 238)	
	rho	p	rho	p
Doctor	0.53	0.000*	0.51	0.000*
Internet	0.60	0.000*	0.64	0.000*
Television	0.37	0.001*	0.61	0.000*
Radio	0.50	0.000*	0.60	0.000*
Newspaper	0.21	0.081	0.50	0.000*
Family and friends	0.52	0.000*	0.70	0.000*
Magazines	0.50	0.000*	0.63	0.000*

*Statistically significant result (using a Bonferroni correction, p < 0.007 required for significance); SCZ, schizophrenia; GP, general practice.

especially for those who do not feel comfortable seeking, or cannot access (e.g. due to rural or remote locations), face-to-face professional help [26]. Close to two thirds of survey respondents in the general population of the USA reported using the Internet for any reason, and health information seeking was by far the most commonly reported online activity [27]. In contrast, our finding of the relative lack of use of the Internet for acquiring health information by people with schizophrenia places them at a potential disadvantage. Although it seems plausible that higher education might predict the use of the Internet as a source of health information, this was only the case for the GP group, a finding consistent with prior research [27,28]. Seeking to understand the barriers and facilitators to accessing the Internet for people with schizophrenia remains a worthwhile endeavour.

Trust in information sources

The comparatively lower level of trust in doctors by participants with schizophrenia in our study warrants further exploration. Trust has long been recognized as a core element of the therapeutic relationship between a doctor and a patient [29–32] and is a significant contributor to therapeutic outcomes [33]. For example, low levels of

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Table 7. Barriers for people with schizophrenia to receiving health information and treatment for physical disorders

- Difficulty by patients in identifying physical symptoms, especially pain [16–19]
- General shortage of general practitioners in Australia [20]
- Ambivalence of medical clinicians to being involved in the care of people with serious mental illness [7,9,23,24]
- Itinerant lifestyle and negative symptoms (e.g. amotivation) impacting on follow up [1,9]
- Physical symptoms assumed to be purely somatization (or delusional) [9,25]
- Belief by psychiatrists that physical health issues will be managed completely by general practitioners and that they have no role in this [9,24]
- Lack of resources encouraging physical health assessment in public mental health settings [7,9]

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patient trust in their doctor have been shown to be associated with poor perceived effectiveness of care, reduced adherence to management recommendations, less doctor–patient contact and poorer continuity of care, less utilization of health care services, greater likelihood to seek a second opinion and worse health by self-report [34–38]. Unfortunately, however, there has been a lack of successful interventions which have been measurably shown to significantly improve trust by patients towards their doctors [39]. Given the persecutory ideation, guardedness, asociality and other negative symptoms experienced by many people with schizophrenia, the challenges in developing trust in the doctor–patient relationship are considerable.

In our study, the proportion of participants in the SCZ group who reported placing a significant amount of trust in the Internet was only about half that of the GP group (35.2% versus 66.5%). The Internet was also lower in the rank order of significantly trusted sources in the SCZ group. The Mann-Whitney test found a significant difference between the two groups with more trust invested in the Internet by participants in the GP group. However, when potential confounders were controlled for in the regression analysis this difference did not reach statistical significance.

Perhaps there is justification in having a degree of healthy reservation in the level of trust placed in the Internet as a health information source. For example, a study evaluating 21 popular websites on depression [26] found that their overall quality was poor, identifying misinformation, misleading information and a lack of balance. The authors highlighted a need for quality assurance mechanisms and suggested the possibility of developing intelligent search engines that use algorithms linked to 'gold standards'.

Finally, while fully utilizing the technical marvels of electronic health resources, it is important also to ensure that the humanity and sense of value of patients be supported and not replaced [40].

Correlation between amount of use of and level of trust in information sources

In our study a significant amount of the variance in the quantity of information gained from a given source (in both groups) was explained by variation in the level of trust invested in that source (Table 6). This was especially so for family and friends in the GP group ($r^2 = 0.49$). It makes intuitive sense that if you trust a source you are more likely to use it, and conversely, that if you use a source and find it reliable you are likely to develop trust in it. However, this correlation is not always the case. A study of 810 college students aged 18–24 [41] found that these young people reported obtaining most of their health information from sources they did not particularly trust, such as friends, the media, and the Internet. On the contrary, health professionals were highly trusted by these students yet were among the least common providers of health information. Furthermore, another study [27] revealed that although physicians remained the most highly trusted source and respondents reported wanting to access them first to obtain specific health information, when asked what they actually did, almost 50% reported going online first as opposed to 10.9% who indicated consulting their physician first.

Limitations

Limitations of this study include recruitment bias (self selection bias; purposive non-probability sampling; cluster sampling), the relatively small sample size, case ascertainment in the SCZ group by consultant psychiatrist diagnosis rather than the employment of a diagnostic instrument, and the inherent limitations of Likert scales. One may not be able to generalize our results to non-health service attendees; however, how non-attendees could be assessed for a diagnosis is a dilemma. It should also be noted that the level of educational attainment is disproportionately

high in the ACT. Based on 2009 Australian Bureau of Statistics data [42], 34.9% of individuals aged 15–64 years in the ACT have a bachelor or post-graduate university degree compared with only 20.5% for Australia. A further potential source of systematic bias was that frequency of contact with a doctor, and what discipline that doctor worked in, were not controlled for in our analysis. Participants with schizophrenia may have had less contact with medical practitioners both within and outside mental health services. Another limitation is the possibility that in the SCZ group some of the reported health 'information' obtained from television, radio, Internet and the print media may have been secondary to psychotic phenomena, such as delusions of reference or auditory hallucinations or other perceptual disturbance. Validity may be questionable when asking people what they do, as in this study, rather than observing what they actually do. Furthermore, while our study invited participants to report on which information sources they were currently using, it should be borne in mind that this may not necessarily be an indication of their preference but rather reflect availability. In addition our study did not distinguish between passively acquiring health information (e.g. while reading a newspaper) versus actively seeking specific information (e.g. after noticing that a mole has changed colour) though in this initial study we were interested in both. Finally, our study also did not specify the type of heath information sought or explore the subgroups within a given information source.

Practical implications

Several practical implications arise from our study. There needs to be investigation into strategies which seek to encourage stronger and more effective links between patients with schizophrenia and a GP, for the provision of accurate health information. Furthermore, clinicians may need to adopt an assertive approach of actively enquiring about physical health issues and then providing relevant and tailored information and recommendations rather than having an expectation that physical symptoms will be disclosed spontaneously. We received positive feedback from many participants with schizophrenia expressing a strong approval of enquiries into, and attempts to find strategies to improve, their physical health. However, GP shortages could present a challenge here. Perhaps mental health services need to consider providing general medical services to their patients.

As family and friends ranked both the second most trusted and second most used health information source for people with schizophrenia, clinicians might consider encouraging and supporting them in a role of providers of health information, as is the case in many chronic neurodegenerative diseases. This might include provision of information sheets and pamphlets which they could share with the patient at a later time.

Finally, as information and communications technologies continue to gather momentum, perhaps integrated community health programmes could be developed which utilize electronic health resources but which are strongly linked to treating clinicians [28]. There may be a role here for allied health services.

Conclusion

There exist significant differences in the reported utilization and trust of health information sources between people with schizophrenia and attendees in GP settings. Given the likelihood of the Internet playing an increasing and dynamic role in health information and service delivery in the future, and the importance of accessing health advice from medically trained clinicians, further research is required to inform on strategies to mitigate this disparity. This is particularly critical in light of the high rates of comorbid physical illness and reduced longevity in people with schizophrenia.

References

1. Brown S, Inskip H, Barraclough B. Causes of the excess mortality of schizophrenia. *Br J Psychiatry* 2000; 177:212–217.
2. Goff DC, Sullivan LM, McEvoy JP *et al*. A comparison of ten-year cardiac risk estimates in schizophrenia patients from the CATIE study and matched controls. *Schizophr Res* 2005; 80:45–53.
3. Lawrence D, Holman CDJ, Jablensky AV. *Preventable physical illness in people with mental illness*. Perth: University of Western Australia, 2001.
4. Felker B, Yazel JJ, Short D. Mortality and medical comorbidity among psychiatric patients: a review. *Psychiatr Serv* 1996; 47: 1356–1363.
5. Ruschena D, Mullen PE, Burgess P *et al*. Sudden death in psychiatric patients. *Br J Psychiatry* 1998; 172:331–336.
6. Harris EC, Barraclough B. Excess mortality of mental disorder. *Br J Psychiatry* 1998; 173:11–53.
7. Goldman LS. Medical illness in patients with schizophrenia. *J Clin Psychiatry* 1999; 60:10–15.
8. Babidge N, Buhrich N, Butler T. Mortality among homeless people with schizophrenia in Sydney, Australia: a 10-year follow-up. *Acta Psychiatr Scand* 2001; 103:105–110.

9. Lambert TJR, Velakoulis D, Pantelis C. Medical comorbidity in schizophrenia. *Med J Aust* 2003; 178:S67–S70.

10. Brown S, Birtwistle J, Roe L, Thompson C. The unhealthy lifestyle of people with schizophrenia. *Psychol Med* 1999; 29:697–701.

11. McCreadie RG, Scottish Schizophrenia Lifestyle Group. Diet, smoking and cardiovascular risk in people with schizophrenia: descriptive study. *Br J Psychiatry* 2003; 183:534–539.

12. Davidson S, Judd F, Jolley D, Hocking B, Thompson S, Hyland B. Cardiovascular risk factors for people with mental illness. *Aust N Z J Psychiatry* 2001; 35:196–202.

13. Leas L. Health behaviours among individuals with schizophrenia and depression. *J Health Psychol* 2007; 12:563–579.

14. Brug J, Aro AR, Oenema A, de Zwart O, Richardus JH, Bishop GD. SARS risk perception, knowledge, precautions, and information sources, the Netherlands. *Emerging Infectious Diseases* 2004; 10: 1486–1489.

15. Voeten HACM, de Zwart O, Veldhuijzen IK *et al*. Sources of information and health beliefs related to SARS and avian influenza among Chinese communities in the United Kingdom and The Netherlands, compared to the general population in these countries. *Int J Behav Med* 2009; 16:49–57.

16. Bunce DFII, Jones LR, Badger LW, Jones SE. Medical illness in psychiatric patients: barriers to diagnosis and treatment. *South Med J* 1982; 75:941–944.

17. Marchland WE. Occurrence of painless myocardial infarction in psychotic patients. *N Eng J Med* 1955; 253:51–55.

18. Talbott JA, Linn L. Reactions of schizophrenics to life-threatening disease. *Psychiatr Q* 1978; 50:218–217.

19. Dworkin RH. Pain insensitivity in schizophrenia: a neglected phenomenon and some implications. *Schizophr Bull* 1994; 20:235–248.

20. Thistlethwaite JE, Leeder SR, Kidd MR, Shaw T. Addressing general practice workforce shortages: policy options. *Med J Aust* 2008; 189:118–121.

21. Australian Government, Medicare Australia. *Annual Report 2008–9* Canberra: Medicare Australia, 2009. [cited 10 April 2010]. Available from URL: http://www.medicareaustralia.gov.au/about/governance/reports/08-09/stats/index.jsp

22. Hippisley-Cox J, Parker C, Coupland C, Vinogradova Y. Inequalities in the primary care of patients with coronary heart disease and serious mental health problems: a cross-sectional study. *Heart* 2007; 93:1256–1262.

23. Goodwin JM, Goodwin JS, Kellner R. Psychiatric symptoms in disliked medical patients. *J Am Med Assoc* 1979; 241:1117–1120.

24. Ananth J. Physical illness and psychiatric disorders. *Compr Psychiatry* 1984; 25:586–593.

25. Jeste DV, Gladsjo JA, Lindamer LS, Lacro JP. Medical comorbidity in schizophrenia. *Schizophr Bull* 1996; 22:413–430.

26. Christensen H, Griffiths K. The Internet and mental health literacy. *Aust N Z J Psychiatry* 2000; 34:975–979.

27. Hesse BW, Nelson DE, Kreps GL *et al.* Trust and sources of health information. *Arch Intern Med* 2005; 165:2618–2624.

28. Dart J, Gallois C, Yellowlees P. Community health information sources – a survey in three disparate communities. *Aust Health Rev* 2008; 32:186–196.

29. Kao AC, Green DC, Zaslavsky AM, Koplan JP, Cleary PD. The relationship between method of physician payment and patient trust. *J Am Med Assoc* 1998; 280:1708–1714.

30. Mechanic D. Changing medical organization and the erosion of trust. *Milbank Q* 1996; 74:171–189.

31. Parsons T. *The social system.* Glencoe, IL: Illinois Free Press, 1951.

32. Peabody FW. The care of the patient. *J Am Med Assoc* 1927; 88: 877–882.

33. Musa D, Schulz R, Harris R, Silverman M, Thomas SB. Trust in the health care system and the use of preventive health services by older black and white adults. *Am J Public Health* 2009; 99:1293–1299.

34. Safran DG, Taira DA, Rogers WH, Kosinski M, Ware JE, Tarlov AR. Linking primary care performance to outcomes of care. *J Fam Prac* 1998; 47:213–220.

35. Hall MA, Dugan E, Zheng B, Mishra AK. Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? *Milbank Q* 2001; 79:613–639.

36. Thom DH, Hall MA, Pawlson G. Measuring patients' trust in physicians when assessing quality of care. *Health Aff* 2004; 23:124–132.

37. Thom DH, Ribisl KM, Stewart AL, Duke DA, Stanford Trust Study Physicians. Further validation and reliability testing of the Trust in Physician Scale. *Med Care* 1999; 37:510–517.

38. O'Malley AS, Sheppard VB, Schwartz M, Mandelblatt J. The role of trust in use of preventive services among low-income among African-American women. *Prev Med* 2004; 38:777–785.

39. Pearson SD, Raeke LH. Patients' trust in physicians: many theories, few measures, and little data. *J Gen Intern Med* 2000; 15:509–513.

40. Looi JCL, Raphael B. Reflections on therapy in the era of the Internet. *Australas Psychiatry* 2007; 15:334–337.

41. LaJoie AS, Ridner SL. Health information and health risk behaviours in a sample of college students. *J Ky Med Assoc* 2009; 107:58–63.

42. Australian Bureau of Statistics. *Education and Work*, *Australia*, *May 2009*. Catalogue no. 6227.0. ABS, Canberra, 2009.

Appendix 2

Oral Presentation:

Australasian Society For Psychiatric

Research

(Dunedin, 2011)

Pandemic influenza: willingness of people with schizophrenia to adopt protective measures

Paul Maguire

Background

Intervention with protective measures can

- **Reduce number of people clinically affected**

- **Reduce hospitalization**

- **Reduce number of deaths**

Nuno et al. JR Soc Interface 2007; Jefferson et al. Cochrane Database Syst Rev 2010

Background

Epidemiological modelling – absence of effective response

Globally
- 7.4 million deaths

Australia
- 40% population clinically affected (8.5 million)
- 2.4% case fatality rate (200,000 deaths)

Influenza pandemics of last century

1918-1919: **Spanish flu** - 40 to 50 million deaths
- ? 50 to 100 million deaths

1957–58: **Asian flu** - 2 million deaths

1968–70: **Hong Kong flu** - 1 million deaths

Avian influenza ("bird flu") – H5N1

Since 2003

- **539 confirmed human cases**
- **318 deaths**
- **Case fatality rate 59%**
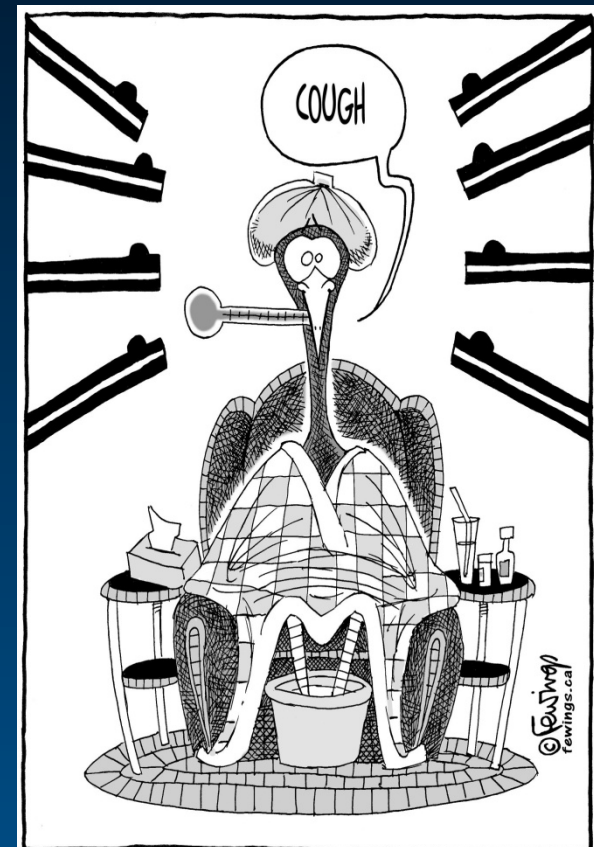
H1N1 09 ("swine flu")

- Not hypervirulent
- Low case fatality rate (≤ 0.01%)
- Population mortality rate = 0.9 per 100,000 (Australia)
- 37,642 confirmed cases (Australia) + 191 associated deaths (cf 2800 per year for seasonal flu)

Australian Government, Department of Health and Aging

Background

People utilizing mental health services

- **Higher mortality rates from *influenza and pneumonia***
  - *Men x 5.4*
  - *Women x 3.4*

- **50% excess risk for *hospitalization* for *influenza***

Lawrence et al. University of Western Australia, 2001

Study – objective and hypothesis

ANU

Objective

- **Willingness** to adopt **protective measures**
- **Predictors and perceived obstacles**
- **People with schizophrenia vs GP attendees**

Hypothesis

- **People with schizophrenia - less willing**
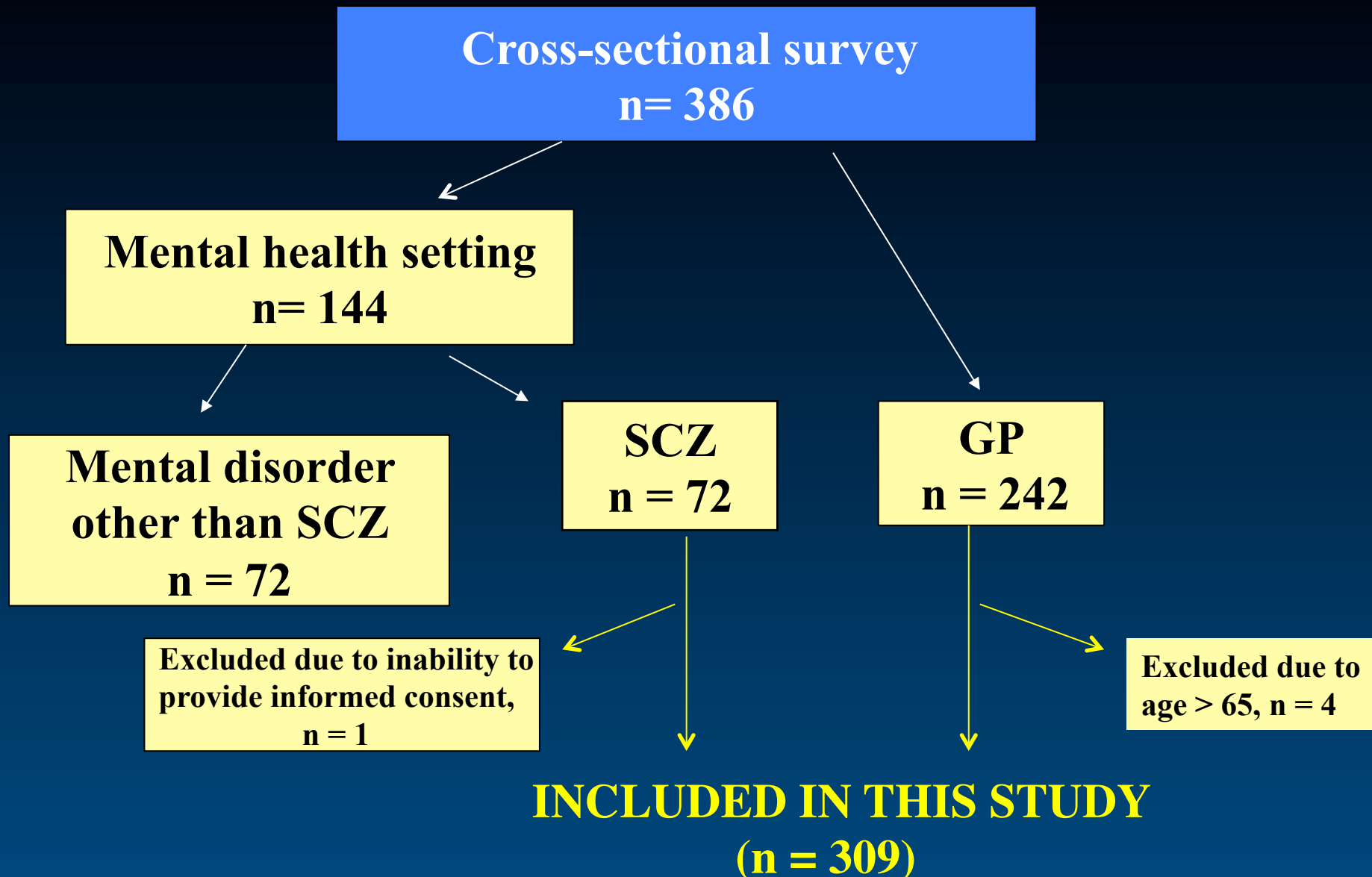
Methodology – principal measures

ANU

5-point Likert- scale

1. Not at all willing
2. A little willing
3. Moderately willing
4. Very willing
5. Extremely willing
6. Don't know (vaccination)

Methodology – statistical analysis

PASW version 18

1. **Independent-samples t-test**

2. **Chi- square test**

3. **Logistic regression**

Socio-demographic characteristics

	SCZ (n=71)	GP (n=238)	Statistic
Age			
Mean	36.6	36.1	t = 0.37, p=0.72
SD	14.0	9.7	
Range	43 (19-62)	47 (18-65)	
Gender			χ^2 = 28.9, p < 0.01 *
Male	70%	34%	
Female	30%	66%	
Highest level of education			χ^2 = 50.7, p < 0.01*
None	11.3%	1.7%	
Year 10 certificate	31.0%	15.1%	
Year 12 certificate	25.4%	20.2%	
TAFE certificate/diploma	23.9%	14.3%	
University degree	8.5%	48.7%	
Currently employed	21.1%	91.7%	χ^2 = 50.3, p < 0.01 *
Lives alone	33.8%	12.2%	χ^2 = 16.5, p < 0.01*
Children in household	5.6%	43.7	χ^2 = 33.2, p < 0.01*
Language other than English spoken in household	20.0%	22.5%	χ^2 = 0.1, p = 0.79

 * Statistically significant result; SD, standard deviation; SCZ, schizophrenia ; GP, general practice

VACCINATION

SCZ = 74%
GP = 80%

ISOLATION

SCZ = 73%
GP = 86%

FACEMASK

SCZ = 55%
GP = 62%

SCZ
GP

% of respondents

Not at all willing   A little willing   Moderately willing   Very willing   Extremely willing

HAND WASHING

SCZ = 89%
GP = 93%

SCZ
GP

% of respondents

45
40
35
30
25
20
15
10
5
0
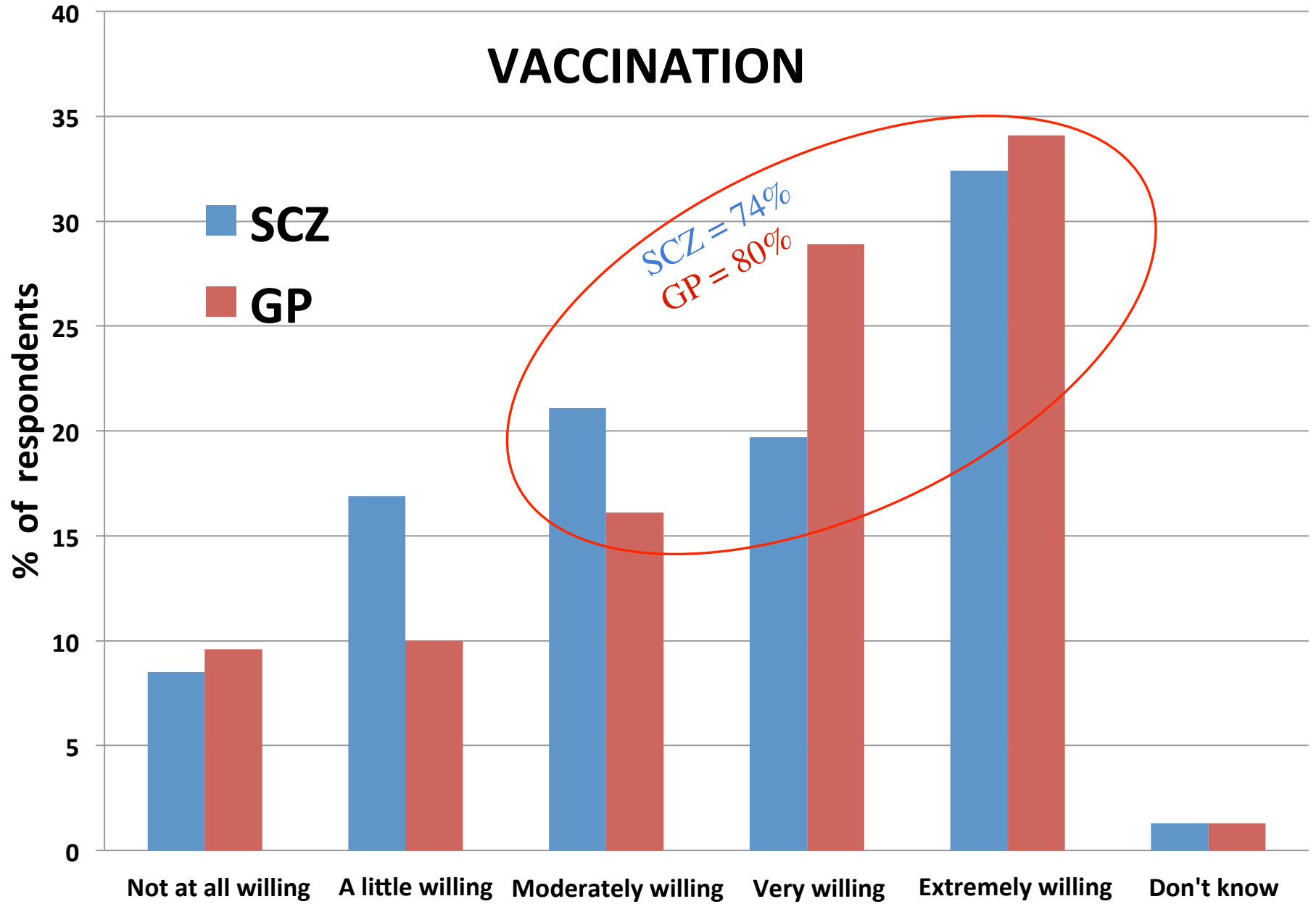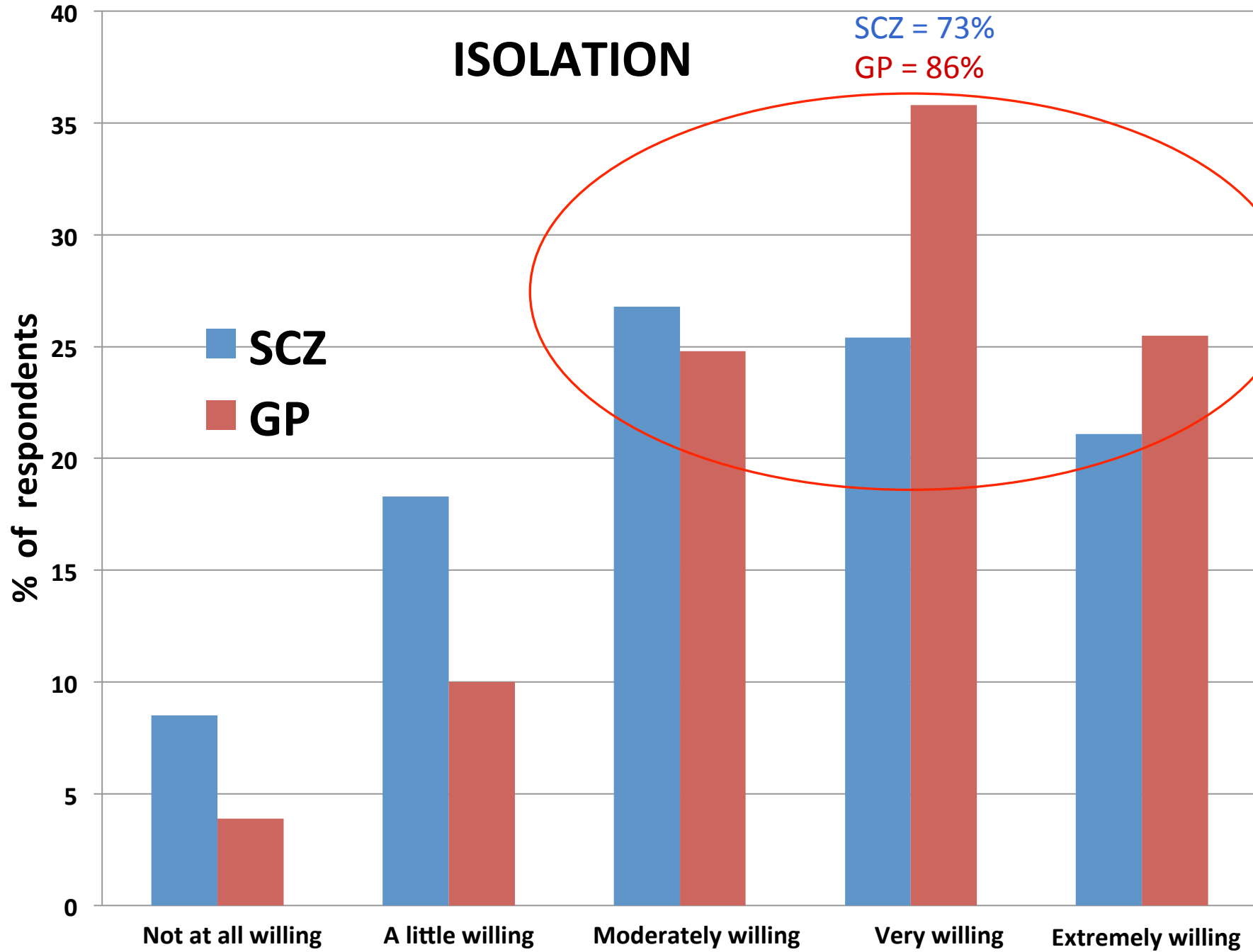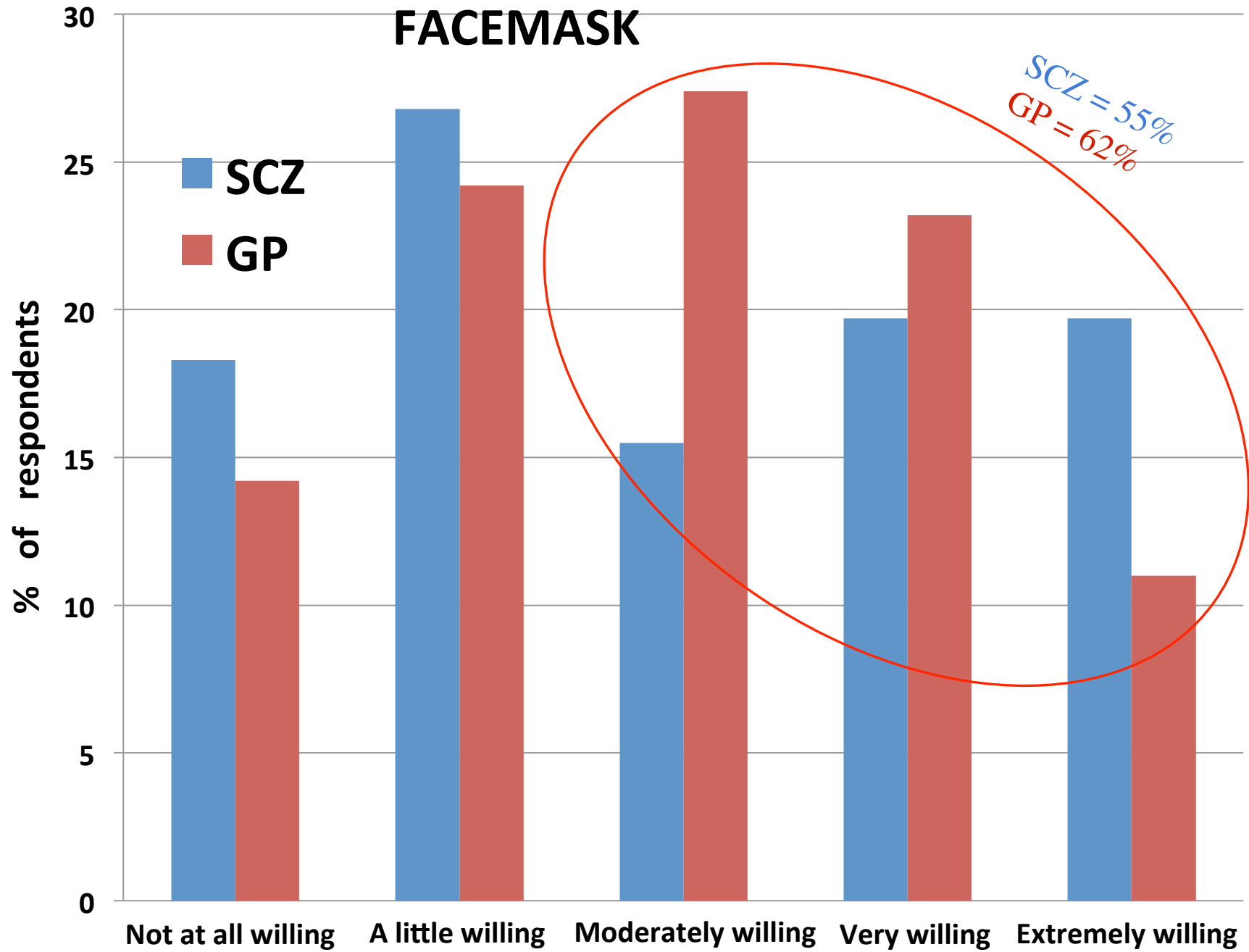
Not at all willing | A little willing | Moderately willing | Very willing | Extremely willing
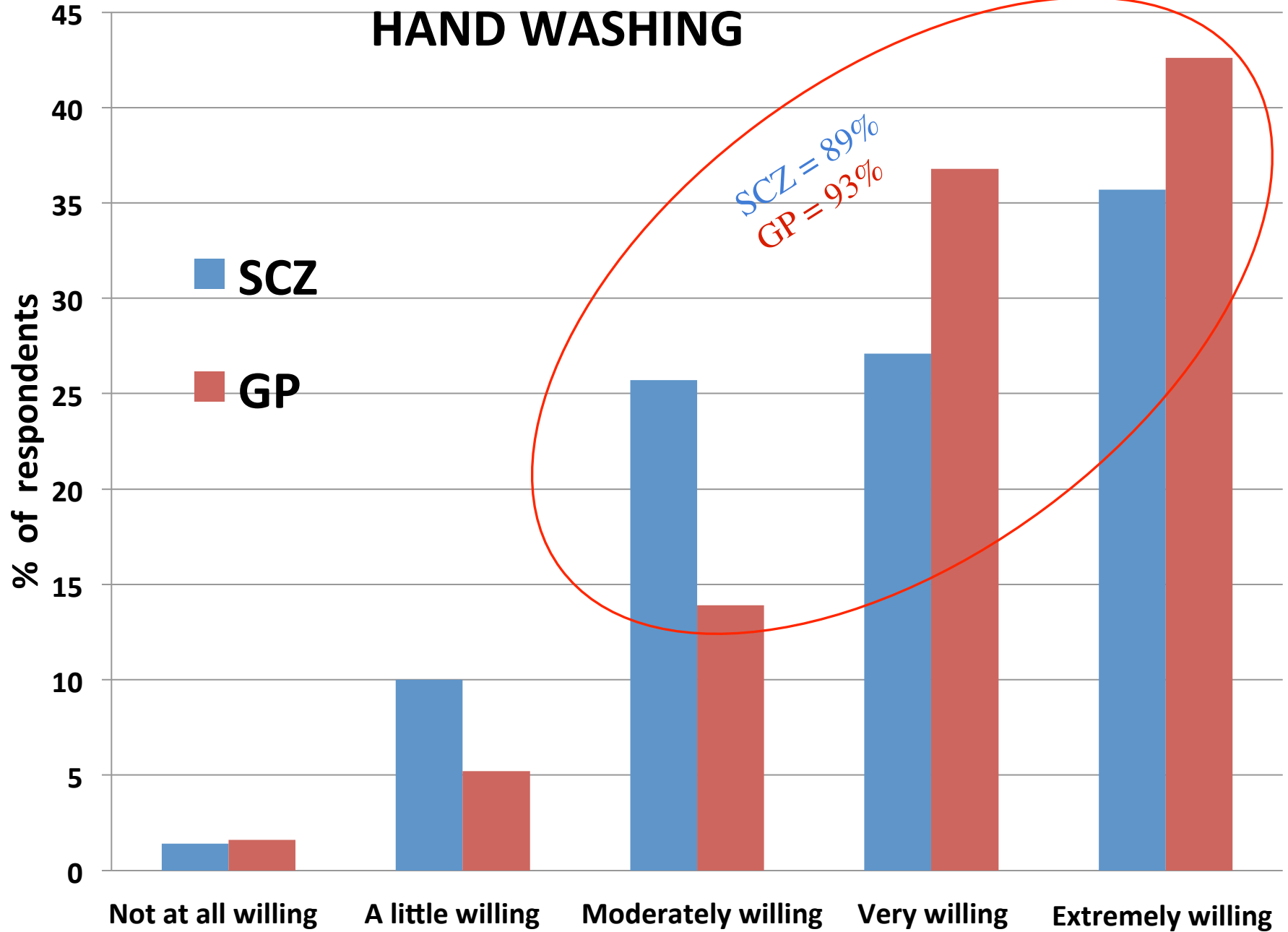
VACCINATION

	SCZ (%) n= 71	GP (%) n = 238	AOR (95%CI)	p
Willing to receive	74.3	80.1	0.41 (0.19-0.88)	0.02*
Perceived as effective	86.6	75.3	1.63 (0.69-3.86)	0.27
Perceived as risky for adverse reaction	38.7	27.5	2.17 (1.03-4.56)	0.04*
Concerned about " catching flu" from vaccination	71.8	50.2	2.19 (1.48-3.25)	0.04*
Self-efficacy	85.5	76.5	0.72 (0.44-1.17)	0.43

* statistically significant level; AOR, adjusted odds ratio; SCZ, schizophrenia; GP, general practice

ISOLATION

	SCZ (%) n= 71	GP (%) n = 238	AOR (95%CI)	p
Willing to be isolated	73.2	86.1	0.41 (0.25-0.65)	0.03*
Perceived as effective	69.7	80.9	0.52 (0.33-0.81)	0.09
Self-efficacy	61.8	72.6	0.44 (0.29-0.66)	0.02*

* statistically significant level; AOR, adjusted odds ratio; SCZ, schizophrenia;
 GP, general practice

FACEMASK

	SCZ (%) n= 71	GP (%) n = 238	AOR (95%CI)	*p*
Willing to wear	54.9	61.6	0.92 (0.49-1.75)	0.81
Perceived as effective	45.5	57.7	0.52 (0.27-1.01)	0.05
Self-efficacy	63.2	66.0	0.90 (0.45-1.79)	0.77

AOR, adjusted odds ratio; SCZ, schizophrenia; GP, general practice

HAND WASHING

	SCZ (%) n= 71	GP (%) n = 238	AOR (95%CI)	p
Willing to increase hand hygiene	88.6	93.2	0.78 (0.25-2.41)	0.66
Perceived as effective	77.3	85.6	0.62 (0.27-1.41)	0.25

AOR, adjusted odds ratio; SCZ, schizophrenia; GP, general practice

Predictors of willingness for SCZ (within-group regression analysis)

Dependent variable	Predictor variable$	AOR
Vaccination willingness	Perceived **self-efficacy**	**3.44**
	Perceived risk of self contracting H1N1 09	**3.48**
	Affective forecast of **fear**	**2.33**
Isolation willingness	Perceived effectiveness	**5.23**
	Perceived **self-efficacy**	**4.89**
Face mask willingness	Perceived overall risk from H1N1 09	**5.61**
	Perceived **self efficacy**	**2.43**
	Affective forecast of **fear**	**3.10**
	Affective forecast of **depressed mood**	**2.49**
	Higher level of education	**0.02#**
Hand washing willingness	Affective forecast of **fear**	**15.20**

$ only statistically significant (p < 0.05) variables included; AOR, adjusted odds ratio

University degree compared with no educational attainment, Year 10 certificate compared with no educational attainment

VACCINATION

ISOLATION

PERCEIVED BARRIER

% of responders

Legend:
- SCZ (blue)
- GP (red)

Categories:
- Loneliness / missing social contact
- Attending work or university
- Attending to child, family or carer duties
- Accessing food or groceries
- Boredom
- Missing leisure pursuits
- Depressing
- Shared accommodation
- Accessing medical needs
- Other
- No difficulty

HAND WASHING

% of responders

PERCEIVED BARRIER

Access to facilities

Remembering

Time

Skin irritation

Waste of resources

Inconvenience

Laziness

Other

No difficulty

SCZ
GP

Summary of findings (SCZ)

Majority willing to

- ❖ be vaccinated (74%)
- ❖ increase hand washing (89%)
- ❖ be isolated (73%)
- ❖ wear face mask (55%)

- **Less willing** than GP attendees for **vaccination** and **isolation**

- Perceived **vaccination** as **riskier** for adverse reaction

- More concerned about **"catching flu"** from **vaccination**

Conclusions

- **Differences** between SCZ and GP groups

- **Hypothesis** partly supported

Acknowledgements

Thanks to

- *Professor Beverley Raphael*
- *Dr Rebecca Reay*
- *Associate Professor Jeffrey Looi*
- *Dr Jeff Cubis*
- *Professor Gerard Byrne*
- *Dr Bruce Shadbolt*
- *Staff of MHACT*
- *ACT general practitioners and staff*

Funding

- *TCH Private Practice Fund*

Appendix 3

Survey: Information Brochure and Poster

Other Information

You can refuse to take part in this study or withdraw from it at any time without affecting your medical care

The results of the study may or may not be of direct benefit to you.

Participation in this study will not result in any medical or hospital costs to you.

The results of the research can be made available to you if you wish.

Principal Researcher

Dr Paul Maguire MBBS FRANZCP
Staff Specialist, The Canberra Hospital
Lecturer, Academic Unit of Psychological Medicine, ANU Medical School

Research Assistant

Ms Rebecca Reay BAppSc(OT) AccOT
Academic Unit of Psychological Medicine

Further questions about this study

If you have any queries or concerns about the questionnaire package, please contact Dr Paul Maguire on 62443876 or
Ms Rebecca Reay on 62443875 or
Ms Peggy Craigie (secretariat) on 62443500 during office hours.

ACT Health

ANU
THE AUSTRALIAN NATIONAL UNIVERSITY

Research Study
Health Beliefs and
Risk Perception

Information Brochure
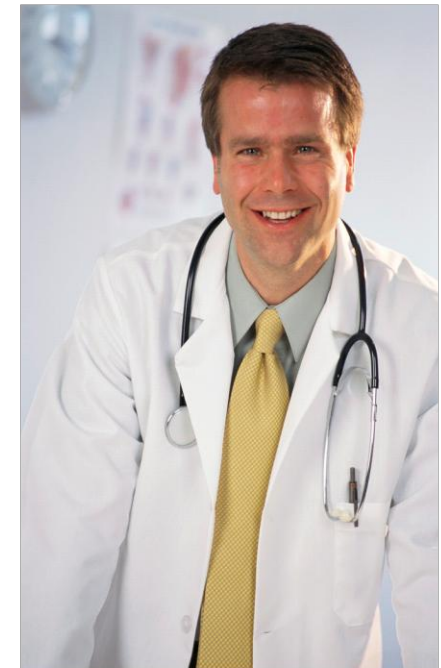
What is the study about?

People's ideas and beliefs about health issues tend to influence what they *do* about their health. This includes how likely they are to seek professional help for an existing illness as well as being involved in activities which may help protect against developing an illness in the first place. This project aims to explore people's health beliefs, emotional reactions and risk perceptions of a range of health issues, with a special focus on influenza.

What would your participation involve?

Attached to this brochure are a questionnaire and a consent form. If you are willing to, simply complete the questionnaire, which will take about 10-20 minutes, sign the consent form and return both to the staff member. You will be rewarded $5.00 for your time and effort in completing this questionnaire.

Confidentiality

Your privacy and identity will be kept confidential at all times and the information you provide will be used only for the purpose of this study. This research project has been approved by both the ANU and the ACT Human Research Ethics Committees. Should you have any problems or queries about the way in which the study is conducted, and do not feel comfortable contacting the research staff, you may contact the ACT Health Human Research Ethics Committee directly. They are located at 11 Moore Street, Canberra City, 2601 or they can be contacted by telephone on (02) 6205 0846.

Potential benefits from the study

It is hoped that a better understanding of what people believe and feel about health issues including health threats will lead to improvements in both prevention and early treatment. A particular focus in this study   is to explore how people perceive the threat of influenza during the current global pandemic and what they would be prepared to do to try to protect against contracting it.

Information on influenza

A web-site with helpful information about influenza and how a person can try to protect against contracting it can be found at:
http:\\www.fightflu.gov.au/questions

Another helpful web-site which includes information on global preparedness and response plan can be found at:
http://www.who.int/crs/disease/influenza

Counselling

If you have concerns about any of the questions within the questionnaire and feel you need to talk to someone, please consider contacting *Lifeline Canberra* on 131114 for counselling or making contact with your GP to arrange counselling.
.

Appendix 4

Survey: Questionnaire

(Items not related to thesis study opaque)

QUESTIONNAIRE

Health Beliefs & Risk Perception

This questionnaire has 5 sections - A B C D E

Please try to answer all questions

It is expected that it will take you about 10 - 20 mins to complete

This survey is for ACT residents aged between 18 and 65 (inclusive)

This questionnaire is designed to seek an understanding of how people think and feel about issues which could significantly impact on their health, with a special focus on influenza.

The information you give to us is **strictly confidential**. You will not be able to be identified in any publications or presentations of the findings of the project.

We thank you very much for agreeing to take part in this research project.

Office Use	
ID No.	
Site code	

Your time and effort are greatly appreciated.

Section A

The questions in this section relate to your sense of well-being.
Please tick the box which <u>best</u> corresponds to your answer.

1. How would you rate your health in general?

1	2	3	4	5
Poor	Fair	Good	Very good	Excellent

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
2. During the last 30 days, about how often did you feel tired out for no good reason?	☐	☐	☐	☐	☐
3. During the past 30 days, about how often did you feel nervous?	☐	☐	☐	☐	☐
4. During the past 30 days, about how often did you feel so nervous that nothing could calm you down?	☐	☐	☐	☐	☐
5. During the past 30 days, about how often did you feel hopeless?	☐	☐	☐	☐	☐
6. During the past 30 days, about how often did you feel restless and fidgety?	☐	☐	☐	☐	☐
7. During the past 30 days, about how often did you feel so restless you could not sit still?	☐	☐	☐	☐	☐
8. During the past 30 days, about how often did you feel depressed?	☐	☐	☐	☐	☐
9. During the past 30 days, about how often did you feel that everything was an effort?	☐	☐	☐	☐	☐
10. During the past 30 days, about how often did you feel so sad that nothing could cheer you up?	☐	☐	☐	☐	☐
11. During the past 30 days, about how often did you feel worthless?	☐	☐	☐	☐	☐

Thankyou – now go to Section B

Section B

The questions in this section relate to how you feel about yourself and how you cope with health threats and difficulties. It also looks at sources of information about health.

Please tick the box which <u>best</u> corresponds to your answer.

1. Generally, are you an optimistic person?

1	None of the time
2	A little of the time
3	Some of the time
4	A lot of the time
5	All of the time

2. When confronted with some kind of new health threat or difficulty I tend to push it aside and try not to think about it.

How well does this statement describe you?

1	Not at all
2	A little
3	Moderately well
4	Very well
5	Extremely well

3. When confronted with some kind of new health threat or difficulty I like to find out more information about it so that I can work out the best way to deal with it.

How well does this statement describe you?

1	Not at all
2	A little
3	Moderately well
4	Very well
5	Extremely well

4. Do you have someone you can turn to for support in times of need?

1	None of the time
2	A little of the time
3	Some of the time
4	A lot of the time
5	All of the time

5. How much information about health matters do you yourself get from the following?

(A) Television

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(B) Radio

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(C) Newspaper

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(D) Internet

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(E) Magazines

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

3

(F) Your doctor

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(G) Family or Friends

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

6. How much _trust_ do you have in the following as sources of information on health matters?

(A) Television

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(B) Radio

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(C) Newspaper

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(D) Internet

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(E) Magazines

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(F) Your doctor

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

(G) Family or Friends

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

7. How much do you feel you are at risk from the following?

(A) A heart attack

5	Not at all
4	A little
3	Moderately
2	A lot
1	Extremely

(B) A motor vehicle accident

5	Not at all
4	A little
3	Moderately
2	A lot
1	Extremely

(C) Cancer

5	Not at all
4	A little
3	Moderately
2	A lot
1	Extremely

Thankyou – now go to Section C

Section C

The questions in this section relate to a pandemic influenza in Australia. The term pandemic influenza refers to an influenza outbreak which spreads rapidly between countries infecting many people at once. It occurs when a new and potentially (but not necessarily) more virulent strain of influenza virus emerges. The human swine influenza (H1N109) was declared a global pandemic by the World Health Organization on June 11th 2009.

For the following questions please tick the box which <u>best</u> corresponds to your answer.

1. What do you see as your own risk of catching human swine flu in Australia during the current global pandemic if you took no special precautions (such as wearing a face mask, having a vaccination, increasing hand washing or isolating yourself) ?

1	Not at all likely
2	A little likely
3	Moderately likely
4	Very likely
5	Extremely likely
6	Don't know

2. If you caught human swine flu in Australia during the current global pandemic, how serious do you think it would it be for you?

1	Not at all serious
2	A little serious
3	Moderately serious
4	Very serious
5	Extremely serious
6	Don't know

3. To what extent do you believe you could avoid catching human swine flu in Australia during the current global pandemic?

1	Not at all
2	A little
3	Moderately
4	A lot
5	Extremely
6	Don't know

4. How vulnerable does it make you feel knowing that there is a global influenza pandemic?

1	Not at all vulnerable
2	A little vulnerable
3	Moderately vulnerable
4	Very vulnerable
5	Extremely vulnerable
6	Don't know

5. If you caught the swine flu during the current outbreak in Australia, how do you think it would affect you emotionally?

(A) Make you feel afraid

1	Not at all afraid
2	A little afraid
3	Moderately afraid
4	Very afraid
5	Extremely afraid

(B) Make you feel depressed

1	Not at all depressed
2	A little depressed
3	Moderately depressed
4	Very depressed
5	Extremely depressed

In the case of an emergency situation such as an influenza pandemic, government authorities might request cooperation from the public in a number of ways.

Please indicate:

6. How willing would you be to receive a flu vaccination?

1	Not at all willing
2	A little willing
3	Moderately willing
4	Very willing
5	Extremely willing
6	Don't know

7. How effective do you think having a flu vaccination would be in preventing you catching the flu during a pandemic outbreak?

1	Not at all effective
2	A little effective
3	Moderately effective
4	Very effective
5	Extremely effective
6	Don't know

8. What do you see as your risk of an adverse reaction from having a flu vaccination?

1	No risk of an adverse reaction at all
2	A small risk of an adverse reaction
3	A moderate risk of an adverse reaction
4	A high risk of an adverse reaction
5	An extreme risk of an adverse reaction
6	Don't know

9. How concerned are you that you may actually get the flu from having a flu vaccination?

1	Not at all concerned
2	A little concerned
3	Moderately concerned
3	Very concerned
5	Extremely concerned

10. How confident are you that once you decided to have a flu vaccination, you would be able to actually go ahead and get it done?

1	Not at all confident
2	A little confident
3	Moderately confident
4	Very confident
5	Extremely confident
6	Not applicable

11. How annoyed with yourself do you think you would you feel if you didn't have the flu vaccination and ended up getting the flu during a pandemic outbreak?

1	Not at all
2	A little
3	Moderately
4	A lot
5	Extremely

12. How much regret would you feel if you didn't get the flu vaccination and ended up getting the flu during a pandemic outbreak?

1	None
2	A little
3	A moderate amount
4	A lot
5	An extreme amount

13. What might be difficult for you about having a vaccination? Please name three things.

1	
2	
3	

14. How willing would you be to isolate yourself from others if needed?

1	Not at all willing
2	A little willing
3	Moderately willing
4	Very willing
5	Extremely willing

15. How effective do you think isolating yourself from others would be in preventing you catching influenza during a pandemic outbreak?

1	Not at all effective
2	A little effective
3	Moderately effective
4	Very effective
5	Extremely effective
6	Don't know

16. How confident are you that once you decided to isolate yourself from others, you would be able to actually go ahead and do this?

1	Not at all confident
2	A little confident
3	Moderately confident
4	Very confident
5	Extremely confident
6	Not applicable

17. What might be difficult for you about isolating yourself from others? Please name three things.

1	
2	
3	

18. How willing would you be to wear a face mask?

1	Not at all willing
2	A little willing
3	Moderately willing
4	Very willing
5	Extremely willing

19. How effective do you think wearing a face mask would be in preventing you catching influenza during a pandemic outbreak?

1	Not at all effective
2	A little effective
3	Moderately effective
4	Very effective
5	Extremely effective
6	Don't know

20. How confident are you that once you decided to wear a face mask, you would be able to actually go ahead and do this?

1	Not at all confident
2	A little confident
3	Moderately confident
4	Very confident
5	Extremely confident
6	Not applicable

21. What might be difficult for you about wearing a face mask? Please name three things.

1	
2	
3	

22. How willing would you be to wash your hands more frequently?

1	Not at all willing
2	A little willing
3	Moderately willing
4	Very willing
5	Extremely willing

23. How effective do you think washing your hands more frequently would be in preventing you catching influenza during a pandemic outbreak?

1	Not at all effective
2	A little effective
3	Moderately effective
4	Very effective
5	Extremely effective
6	Don't know

24. What might be difficult for you about washing your hands more frequently? Please name three things.

1	
2	
3	

25. What do you see as possible outcomes if you caught influenza during a pandemic outbreak?

(A) You would have a full recovery with no residual damage to your health?

1	Not at all likely
2	A little likely
3	Moderately likely
4	Very likely
5	Extremely likely
6	Don't know

(B) You would need for some time off work or usual home duties?

1	Not at all likely
2	A little likely
3	Moderately likely
4	Very likely
5	Extremely likely
6	Don't know

(C) It could cause you to die?

1	Not at all likely
2	A little likely
3	Moderately likely
4	Very likely
5	Extremely likely
6	Don't know

26. Please try to name three symptoms which a pandemic influenza might produce in a person who caught it.

1	
2	
3	

27. How long do you think a human swine influenza illness would last on average in an otherwise healthy person? Please tick one box only.

1	One week
2	Three weeks
3	Three months
4	Don't know

28. Have you or someone close to you ever suffered from a serious influenza in the past?

| 1 | Yes |
| 2 | No |

29. Overall, what do you see as your risk from human swine influenza if you took no protective measures?

1	No risk at all
2	A small risk
3	A moderate risk
4	A high risk
5	An extreme risk

30. Do you feel you've got so many worries on your mind at the moment that if you were notified about a serious health threat such as an outbreak of a virulent strain of influenza you just couldn't deal with it?

1	Not at all
2	A little
3	Moderately
4	A lot
5	Extremely

31. Do you suffer from any current serious medical illnesses?

| 1 | Yes (please list) | 2 | No |

1	
2	
3	

Thankyou – now go to Section D

Section D

1. Do you suffer from a mental illness or mental health problem?

| 1 | Yes |
| 2 | No |

If you answered **"YES",** please answer questions below**.**

If you answered **"NO",** please go now to Section E

2. What do you see as your main mental illness or mental health problem?

……………………………………………………………………………………………………

3. Has you doctor confirmed this diagnosis?

| 1 | Yes | | 2 | No |

4. How would you rate your mental health in general? (Please tick one box below)

| 1 | 2 | 3 | 4 | 5 |
| Poor | Fair | Good | Very good | Excellent |

5. For the following questions please circle the number which best corresponds to your views about this illness.

(A) How much does your illness affect your life?

0   1   2   3   4   5   6   7   8   9   10

No affect   Severely affects
 at all   my life

(B) How long do you think your illness will continue for?

0   1   2   3   4   5   6   7   8   9   10

A very short   Forever
   Time

(C) How much control do you think you have over your illness?

0   1   2   3   4   5   6   7   8   9   10

Absolutely   Extreme amount
no control   of control

(D) How much do you think your treatment can help your illness?

0   1   2   3   4   5   6   7   8   9   10

Not at all   Extremely helpful

9

(E) How much do you experience symptoms from your illness?

0	1	2	3	4	5	6	7	8	9	10

No symptoms at all   Many severe symptoms

(F) How concerned are you about your illness?

0	1	2	3	4	5	6	7	8	9	10

Not at all concerned   Extremely concerned

(G) How well do you feel you understand your illness?

0	1	2	3	4	5	6	7	8	9	10

Don't understand at all   Understand very clearly

(H) How much does your illness affect you emotionally? (eg does it make you angry, scared upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10

Not at all affected emotionally   Extremely affected emotionally

----

(I) Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. The most important causes for me:

1	
2	
3	

Thankyou – now go to Section E.

Section E

Thank you for supplying the following background information.

1. Today's date: __ __ / __ __ / __ __

2. Your date of birth: __ __ / __ __ / __ __

(<u>Please tick</u> appropriate box)

3. Your gender   ☐ 1 Male ☐ 2 Female

4. Are there children in your household?   ☐ 1 Yes ☐ 2 No

5. Are there people aged over 65 years in your household?

      ☐ 1 Yes ☐ 2 No

6. Are there languages other than English spoken at home?   ☐ 1 Yes ☐ 2 No

7. Are you living alone?   ☐ 1 Yes ☐ 2 No

8. Are you employed?   ☐ 1 Yes ☐ 2 No

9. What was your highest level of education?

1	None
2	Year 10 certificate (School certificate)
3	Year 12 certificate (High school certificate)
4	TAFE certificate or diploma
5	University degree / equivalent

10. What is your estimated yearly household (gross) income?

1	< $20,000
2	$20,000 - $40,000
3	$40,000 - $60,000
4	$60,000 - $80,000
5	$>80,000

Final Checklist

	Have you read the patient information sheet?
	Have you read and signed the consent form?
	Have you completed all questions in the relevant sections?

Thank you – you have now finished.

**Please hand the questionnaire to the staff member
(receptionist in general practice/ private psychiatry practice setting)**

Appendix 5

Survey: Ethics Approval

ACT HEALTH HUMAN RESEARCH ETHICS COMMITTEE

Outcome of Consideration of Protocol

Submission No: ETH.4/09.356   **Date of Approval: 15 June 2009**

Project Title:
Health Beliefs and Risk Perception: Pandemic Influenza Threat in Australia

Submitted by:
Dr Paul Maguire

Your project was considered by the ACT Health Human Research Ethics Committee and Approved for a period of 10 months

Review due: 2010

The Ethics Committee require as part of the review process that:

- At regular periods, and not less frequently than annually, Principal Investigators are to provide reports on matters including:

  - security of records

  - compliance with approved consent procedures and documentation

  - compliance with other approved procedures.

  - as a condition of approval of the protocol, that Investigators report immediately:

  - adverse affects on subjects

  - proposed changes in the protocol

  - unforeseen events that might affect continued ethical acceptability of the project.

- All published reports to carry an acknowledgement stating:

  - approved on 15 June 2009 by the ACT Health Human Research Ethics Committee.

DR ELIZABETH GRANT AM, CHAIR   22 June 2009

From:	aries@anu.edu.au
Sent:	Tuesday, 23 June 2009 4:30 PM
To:	Maguire, Paul
Cc:	beverley.raphael@anu.edu.au; human.ethics.officer@anu.edu.au
Subject:	Human Ethics Protocol 2009/333

THIS IS A SYSTEM-GENERATED E-MAIL. PLEASE DO NOT REPLY. SEE BELOW FOR E-MAIL CONTACT DETAILS.

Dear Dr Paul Maguire,

Protocol: 2009/333
Health Beliefs and Risk Perception

I am pleased to advise you that your Human Ethics protocol received approval by the Deputy Chair of the Human Research Ethics Committee on 23/06/2009.

For your information:

1.   Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved.
Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.

2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.

3. Please notify the Committee immediately if any unforeseen events occur that might affect continued ethical acceptability of the research work.

4. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Yolanda

Yolanda Shave
Ethics Manager
Office of Research Integrity
Research Office
Chancelry Building 10B
The Australian National University
Canberra, ACT 0200

E:human.ethics.officer@anu.edu.au or
yolanda.shave@anu.edu.au
W: http://www.anu.edu.au/ro/ORI/Human/human_index.php
T: (02) 6125 7945
F: (02) 6125 4807

CRISCOS Provider Code: 00120C

Appendix 6

Survey: Ethics Committee Approved

Consent Forms

Consent form for participants attending general practices settings

Consent Form

I, _____
   (name of participant)

of _____   _____
   (street)   (suburb / town)

_____
   (state / territory & postcode)

have been invited to participate in a research project entitled: Health Beliefs and Risk Perception.

Principal Investigator: Dr Paul Maguire The Canberra Hospital (02) 62443876

Research assistant: Ms Rebecca Reay The Canberra Hospital (02) 62443875

In relation to this project I have read the patient information brochure and have been informed of the following points:

1. Approval has been given by both the ANU Human Research Ethics Committee and the ACT Health Human Research Ethics Committee.

2. The aim of the project is to explore people's beliefs, emotional reactions to and risk perception regarding health threats.

3. The results of this study may, or may not, be of direct benefit to me.

4. My involvement will consist of completing a questionnaire relating to my ideas and emotional reactions about a number of health threats and illnesses.

5. Should I develop a problem which I am concerned may be connected with my involvement in the project, I am aware that I may contact Dr Paul Maguire or Ms Rebecca Reay on the numbers given above.

6. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting research staff, I am aware that I may contact the secretariat of the ACT Human Research Ethics Committee on: (02) 6205 0846 or The Canberra Hospital Research Office on 62444043.

7. I am aware that I can withdraw from this project at any time or refuse to take part in it without affecting my medical care. I may cease my involvement in this project if I find the questions in some way upsetting for me and no longer want to participate.

8. Participation in this project will not result in any extra medical or hospital costs to me.

9. I understand that information I give in this project will be de-identified and reported in a general way with my involvement and identity not being revealed.

After considering all these points I accept the invitation to participate in this project.

Name: _____   Date: _____
            (please print)

Signature: _____
              (of participant)

Consent form for participants in mental health settings

Consent Form

I, _____

   (name of participant)

of _____   _____

   (street)   (suburb / town)

_____

   (state / territory & postcode)

have been invited to participate in a research project entitled: Health Beliefs and Risk Perception.

Principal Investigator: Dr Paul Maguire The Canberra Hospital (02) 62443876

Research assistant: Ms Rebecca Reay The Canberra Hospital (02) 62443875

In relation to this project I have read the patient information brochure and have been informed of the following points:

1. Approval has been given by both the ANU Human Research Ethics Committee and the ACT Health Human Research Ethics Committee.

2. The aim of the project is to explore people's beliefs, emotional reactions to and risk perception regarding health threats.

3. The results of this study may, or may not, be of direct benefit to me.

4. My involvement will consist of completing a questionnaire relating to my ideas and emotional reactions about a number of health threats and illnesses. I give consent for the researcher or assistant to contact my psychiatrist to confirm the diagnosis of my mental health problem for the questionnaire.

5. Should I develop a problem which I am concerned may be connected with my involvement in the project, I am aware that I may contact Dr Paul Maguire or Ms Rebecca Reay on the numbers given above.

6. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting research staff, I am aware that I may contact the secretariat of the ACT Human Research Ethics Committee on: (02) 6205 0846 or The Canberra Hospital Research Office on 62444043.

7. I am aware that I can withdraw from this project at any time or refuse to take part in it without affecting my medical care. I may cease my involvement in this project if I find the questions in some way upsetting for me and no longer want to participate.

8. Participation in this project will not result in any extra medical or hospital costs to me.

9. I understand that information I give in this project will be de-identified and reported in a general way with my involvement and identity not being revealed.

After considering all these points I accept the invitation to participate in this project.

Name: _____   Date: _____

(please print)

Signature: _____

Appendix 7

Survey: Survey Resource Group (SRG)

Approval

CANBERRA
HOSPITAL

A division of ACT Health

Dr Zsuzsoka Kecskes
Chair
Survey Resource group
Canberra Hospital

To: Dr Paul Maguire

Date: 1st May 2009

Approval of survey: **Health Beliefs and Risk Perception Survey**

Dear Dr Maguire,

Thank you for submitting your survey to the Survey Resource Group of the Canberra Hospital.
On behalf of the Group, I am pleased to advise you that the survey has been approved.

For your information:

Please notify the committee of any changes you make to your survey during the course of your study.

The validity of the current approval is 2 years maximum from the date of this letter.

Please submit a brief report to the Survey Resource Group when you complete or cease working on the survey.

On behalf of the group, I would like to wish you all the best with your study.

Yours sincerely

Zsuzsoka Kecskes, Dr med FRACP PhD

Chair Survey Resource Group
Clinical Director, Department of Neonatology
Associate Professor
Australian National University Medical School
The Canberra Hospital, Woden, ACT, 2605
Australia
Tel: (02) 6244 4056
Fax: (02) 6244 3112
E-mail: zsuzsoka.kecskes@act.gov.au

Appendix 8

Survey: Funding Approval

Private Practice Fund Administration
Yamba Drive, Garran ACT 2605
PO Box 11 Woden ACT 2606
Phone: (02) 6244 3537 Fax: (02) 6285 3453
Website: www.health.act.gov.au
ABN: 82 049 056 234

CANBERRA
HOSPITAL
A division of ACT Health

14 July 2009

Dr Paul Maquire
Mental Health
Building 15
THE CANBERRA HOSPITAL

Dear Dr Maquire

Re: Health Beliefs and Risk Perception: Pandemic Influenza Threat in Australia

Your application was discussed at the meeting of the Minor Grants Sub Committee on Tuesday 14 July 2009.

The Private Practice fund Administration Committee agreed to fund your research project for $2,500

Please provide a progress research report to the Research Office, 12 months after receipt of this offer. Any publication arising out of the research should include acknowledgement of support from the Private Practice Fund

Please find attached a copy of your de-identified Assessor's Report for your information.

Please contact Sally Winter in the Private Practice Fund Office on 62443537 if you require further details

Kind Regards

Dr Sanjiv Jain
Chairman
Private Practice Fund Administration Committee

CC   PPF Administration Committee
       Ms Sue Calcraft

Appendix 9

Survey: Socio-demographic Variables as Predictors of Information Gained from, or Trust Invested in, a Given Information Source

Socio-demographic predictors of a substantive amount of health information obtained from a given source: SCZ within-group multiple logistic regression analysis

	Doctor		Internet		Television		Radio		Newspaper		Magazines		Family & Friends	
	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*
Age	1.05	0.05	0.98	0.47	1.02	0.44	1.04	0.18	1.04	0.20	1.05	0.12	0.97	0.20
Gender (male)	1.13	0.82	2.13	0.20	1.09	0.62	1.72	0.33	1.06	0.93	0.79	0.69	1.07	0.90
Living alone	0.95	0.92	0.88	0.81	**4.42**	**0.01***	2.29	0.11	0.47	0.28	0.97	0.96	0.63	0.36
Employed	4.47	0.08	0.90	0.86	1.06	0.92	0.81	0.73	1.67	0.45	1.65	0.43	0.99	0.99
Highest level of education	-	0.86	-	0.14	-	0.21	-	0.21	-	0.55	-	0.26	-	0.54
Household income	-	0.63	-	0.64	-	0.83	-	0.87	-	0.17	-	0.50	-	0.45
Children in household	2.15	0.52	1.91	0.53	0.91	0.93	0.55	0.61	4.58	0.15	3.19	0.27	2.74	0.39
Non-English language spoken at home	2.02	0.28	0.42	0.22	0.87	0.81	0.74	0.65	1.12	0.88	1.84	0.34	1.24	0.72

* statistical significance ($p < 0.05$); Exp(B), exponential of regression coefficient B; SCZ, schizophrenia

Socio-demographic predictors of a substantive level of trust in a given health information source: SCZ within-group logistic regression analysis

	Doctor		Internet		Television		Radio		Newspaper		Magazines		Family & Friends	
	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*
Age	1.07	0.12	0.96	0.26	1.00	0.92	1.01	0.59	1.01	0.75	1.02	0.62	0.95	0.13
Gender (male)	0.67	0.64	0.56	0.49	1.28	0.54	0.91	0.80	1.26	0.78	0.82	0.80	**0.15**	**0.01***
Living alone	0.56	0.44	1.32	0.71	1.61	0.64	1.06	0.91	2.27	0.25	0.90	0.88	1.00	> 0.99
Employed	2.07	0.95	0.09	0.09	0.89	0.28	0.83	0.41	0.66	0.68	0.82	0.47	2.23	0.35
Highest level of education	-	0.65	**-**	**0.03***	-	0.91	-	0.81	-	0.72	-	0.40	-	0.31
Household income	-	0.96	-	0.71	-	0.66	-	0.76	-	> 0.99	-	0.60	-	0.59
Children in household	31.26	> 0.99	1.91	0.94	1.39	0.64	0.56	0.62	< 0.01	> 0.99	0.77	0.88	2.58	0.70
Non-English language spoken at home	1.61	0.64	0.87	0.13	1.44	0.75	2.82	0.20	1.58	0.59	2.14	0.30	1.67	0.43

* statistical significance (*p* < 0.05); Exp(B), exponential of regression coefficient B; SCZ, schizophrenia

Socio-demographic predictors of a substantive amount of health information obtained from a given source: GP within-group multiple logistic regression analysis

	Doctor		Internet		Television		Radio		Newspaper		Magazines		Family & Friends	
	Exp(B)	p	Exp(B)	p	Exp(B)	p	Exp(B)	p	Exp(B)	p	Exp(B)	p	Exp(B)	p
Age	**1.03**	**0.01***	0.98	0.08	1.01	0.60	1.01	0.34	1.01	0.56	1.00	0.93	**0.97**	**0.01***
Gender (male)	**0.47**	**0.03***	0.60	0.07	0.60	0.07	1.06	0.86	1.10	0.76	0.71	0.31	1.29	0.36
Living alone	0.91	0.84	1.30	0.56	1.30	0.56	0.79	0.62	1.18	0.71	1.51	0.34	0.54	0.12
Employed	1.42	0.31	1.29	0.39	1.29	0.39	1.00	0.99	**0.43**	**0.03***	0.85	0.62	1.05	0.86
Highest level of education	-	**0.03***	-	**0.01***	-	0.60	-	0.71	-	0.10	-	0.96	-	0.16
Household income	-	0.62	-	0.26	**-**	0.91	**-**	**0.01***	-	0.06	-	0.06	-	0.70
Children in household	0.81	0.53	1.04	0.89	1.04	0.89	1.18	0.61	1.48	0.18	**2.53**	**0.01***	0.62	0.08
Non-English language spoken at home	0.84	0.65	0.84	0.60	0.84	0.60	0.62	0.25	1.52	0.21	**2.60**	**0.01***	**2.48**	**< 0.02***

* statistical significance ($p < 0.05$); Exp(B), exponential of regression coefficient B; GP, general practice

Socio-demographic predictors of a substantive level of trust in a given health information source: GP within-group multiple logistic regression analysis

	Doctor		Internet		Television		Radio		Newspaper		Magazines		Family & Friends	
	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*	Exp(B)	*p*
Age	1.05	0.11	1.01	0.42	1.01	0.19	1.01	0.20	1.00	0.66	0.17	0.18	**0.97**	**0.01***
Gender (male)	0.62	0.49	0.83	0.51	1.47	0.17	1.22	0.48	1.09	0.77	0.77	0.38	1.32	0.35
Living alone	0.26	0.07	0.91	0.86	0.96	0.92	**2.27**	**0.04***	1.73	0.17	1.05	0.91	0.47	0.06
Employed	**4.84**	**0.03***	0.95	0.87	0.90	0.72	0.93	0.80	1.19	0.54	1.15	0.65	1.56	0.13
Highest level of education	-	0.38	-	0.48	-	0.47	-	0.33	-	0.18	-	0.18	-	0.36
Household income	-	0.64	-	0.53	-	0.95	-	0.54	-	0.92	-	0.62	-	0.64
Children in household	2.81	0.20	1.52	0.11	1.10	0.72	0.81	0.44	0.84	0.50	1.13	0.67	0.86	0.59
Non-English language spoken at home	0.37	0.21	1.07	0.83	1.39	0.31	0.68	0.27	1.18	0.60	1.33	0.39	1.84	0.09

* statistical significance ($p < 0.05$); Exp(B), exponential of regression coefficient B; GP, general practice

Appendix 10

Qualitative Study: Recruitment Letter

Dear ....

I am writing to find out if you would be interested in taking part in a small research project. It is a follow-up study on the *Health Beliefs and Risk Perception: Pandemic Influenza Threat in Australia* survey questionnaire you kindly completed in 2009. Your involvement in that project was much appreciated.

The current study aims to explore in more detail what people themselves think and feel about influenza, including what they believe would be helpful in dealing with it. For example, if you wanted to find out more information about a flu going around this winter, how would you go about this?

Please have a read of the information brochure for more details. In appreciation of your time, effort and travel costs you would be awarded a payment of $30.00 for your participation.

Your decision to take part or not to take part in the study is purely voluntary and will not affect your ongoing medical / psychiatric care in any way. You can choose to withdraw from the research project at any time and information you have given will removed and destroyed if this is your wish.

I plan to phone you over the next week or so to find out if you would like to go ahead.

Yours sincerely

Dr Paul Maguire
Australian National University Medical School
Ph: (02) 62443500

Date..........

Appendix 11

Qualitative Study: Information Brochure

RESEARCH STUDY

INFLUENZA

What is the study about?

This research study aims to explore the views of people with schizophrenia on influenza, both seasonal flu (which often occurs in winter) and more widespread flu (like the Swine Flu in 2009), called pandemic influenza. The study is interested in people's views on what information is important to know about influenza and how they would go about finding out more about a flu if they wanted to. The study aims to explore how likely people think they are to catch the flu and how serious they think this would be for them if they did. The study is also looking at what people think and feel about various precautionary measures to help protect against flu, for example, vaccination and increased hand washing. The scientific aspects of the study and its findings may be published in a scientific journal, presented at a conference or be entered into a thesis report.

What would your participation involve?

If you agree to participate in the study you would be interviewed by the study's principal researcher, Dr Paul Maguire, at your local mental health centre, during normal working hours. This interview, exploring your views on influenza, is expected to last about 30-60 minutes. Dr Maguire would take notes during the interview in order that none of your views and suggestions are missed. These notes will not have your name on them and you will not be identified in any results or reports arising from the research project. Your views about this important health issue do matter and any information you provide would be very useful in identifying themes about what you and others think about influenza. The researchers are interested in these themes and no personal information about you will be entered into any reports or publications. Although the study may or may not directly benefit you, it will assist in finding improved ways of helping people with the flu and planning for serious influenza outbreaks, such as pandemics. In appreciation of your time, effort and travel costs, you would be awarded a payment of $30 for your participation. Your decision to take part or not to take part in the study is purely voluntary and will not affect your ongoing medical / psychiatric care in any way. You can choose to withdraw from the research project at any time prior to publication or presentation of results, and information you have given will be removed and destroyed if this is your wish.
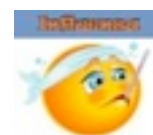
Confidentiality

Your privacy and identity will be kept confidential at all times and the information you provide will be used only for the purpose of this study, as far as the law allows. Scientific data relating to the study will be securely stored on an ANU computer (protected by a password known only to the principal researcher) for at least five years following any publication arising from the study.

Who should I contact if I have concerns about the conduct of this study?

The ethical aspects of this research project have been approved by the ANU and ACT Health Human Research Ethics Committees. If you have any concerns or complaints about the conduct of this study, and do not feel comfortable discussing this with study staff, you may contact the Committee secretariat who is nominated to receive complaints about research projects. You should contact the secretariat on 6174 7968 or acthealth-hrec@act.gov.au

Counselling

Although the interview will be conducted in a relaxed, confidential and supportive atmosphere, if you become upset or troubled in any way following the interview and feel the need to speak to someone, please consider contacting *Lifeline Canberra* on 131114 or making contact with your GP.

Principal researcher

Dr Paul Maguire MBBS FRANZCP
Staff Specialist ACT Health
Lecturer, ANU Medical School

Further questions about this study

The name of the research project is *Understanding how people with schizophrenia view influenza - a qualitative study*. If you have any questions or concerns about this study please contact Paul Maguire through (02) 62443500 or paul.maguire@act.gov.au

Appendix 12

Qualitative Study: Topic Guide

UNDERSTANDING HOW PEOPLE WITH SCHIZOPHRENIA VIEW INFLUENZA - A QUALITATIVE STUDY

IN-DEPTH INTERVIEW TOPIC GUIDE

Introduction

Thank you very much for agreeing to be involved in this research study. Our aim with this research is to find out what people with schizophrenia think and feel about the flu, including how they would obtain information about it and what they think would be useful in dealing with it. Any information you provide will be helpful. It it will assist in finding improved ways of helping people with the flu, both the seasonal flu and those more widespread flus called pandemics. This interview can go on for any time up to an hour. I will take some notes during the interview so that I don't miss any of your views and ideas but these notes will not have your name on them and will only be used for the aims of the study. Your confidentiality will be protected at all times. I also need you to sign a consent form if you are happy to.

Key Interview Questions

1. Have you ever had the 'flu? If yes --- > Were you very sick with it? Did you see a doctor? Did you find this helpful? (how and how not?) Did you try to find out information about the flu? How did you go about doing this? If never had flu --- > If you wanted to find out more information about flu how would you go about this?

2. Sometimes there are flus called pandemics, which often start overseas and spread around the world affecting a large number of people; there was one in 2009 called Swine Flu which came to Australia; do you remember hearing about it? Can you recall how you heard about it (e.g. doctor, Internet, TV, radio, family/friends, newspaper etc).

3. Did you catch the Swine Flu or know anyone who did? Did you think you might get it? What did you think and what did you feel about this pandemic flu. Were you worried about it being serious for you if you caught it? What was the experience like for you knowing that it reached Australia? What are your thoughts on how likely it is for you to get the seasonal flu. How serious do think it would be for you if you did come down with it?

4. People talk about it being helpful during flu outbreaks to wash your hands thoroughly, wear a face mask or to keep away from others – has anyone talked to you about any of this kind of thing. What do you think and feel about these things? What are your thoughts generally on things you can do to try to avoid catching the flu? How do you feel about having a vaccination for this reason, especially if it were one of those big flus, a pandemic flu, we spoke about earlier?

5. Do you think or worry about possible future flus like a bird flu pandemic coming to Australia. If this happened what are your thoughts on how likely it would be for you to catch it? If you did how serious do you think it would be for you?

6. What information about flu do you think is important to know?

Closing Question

Is there anything else about influenza you feel is important or that you would like to tell me which I haven't asked about?

Thank you for your time and participation.

Appendix 13

Qualitative Study: Ethics Approval

Dr Paul Maguire
AUPAD
Building 4, Level 2
Canberra Hospital
Garran ACT 2605

Dear Dr Maguire

ETH.7.14.158

The ACT Health Human Research Ethics Committee considered the proposed:

Understanding how people with schizophrenia view influenza – a qualitative study at its meeting of 7 July 2014.

I am pleased to inform you that, following further correspondence, your application has been approved out of session.

Approval includes:

- HREC Application
- Participant Information Sheet
- Consent Form
- Recruitment Letter
- In Depth Interview Guide

I confirm that the ACT Health Human Research Ethics Committee is constituted according to the National Statement on Ethical Conduct in Human Research 2007 and is certified for single review of multi-centre clinical trials. ACT Health HREC operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

I attach for your records an Outcome of Consideration of Protocol form.

You are reminded that this letter grants ethical approval only. The research project must not commence at any non-ACT Health site until site-specific governance approval has been granted.

Yours sincerely

Louise Morauta PSM PhD
Chair
ACT Health Human Research Ethics Committee

16 July 2014

ACT HEALTH HUMAN RESEARCH ETHICS COMMITTEE

Outcome of Consideration of Protocol

Submission No: ETH.7.14.158   **Date of Approval:**   16 July 2014

Project Title: Understanding how people with schizophrenia view influenza – a qualitative study

Submitted by: Dr Paul Maguire

Your project was considered by the ACT Health Human Research Ethics Committee and Approved for a period of 5 years from July 2014 to July 2019

First Annual Review due: July 2015

Conditions of Approval:

- At regular periods, and not less than annually, Principal Investigators are to provide reports on matters including:

  - adverse affects on participants

    - Serious Adverse Events as they occur on site

    - SUSAR/Line Listing reports

  - unforeseen events that could affect the continued ethical acceptability of the project

  - proposed changes in the protocol

  - updates of the investigator brochures

  - continued compliance with approved consent procedures and updates of consent documentation

  - Data Safety Monitoring Board Reports (where applicable)

  - security of records

  - updated insurance coverage

  - compliance with other approved procedures.

- All published reports are to carry an acknowledgement stating:

  - Approved by ACT Health Human Research Ethics Committee on 16 July 2014

Louise Morauta PSM PhD
Chair
ACT Health Human Research Ethics Committee

16 July 2014

Appendix 14

Qualitative Study: Ethics Committee

Approved Consent Form

Consent form

I, _____
              (name of participant)

of _____   _____
              (street)   (suburb / town)

_____
       (state / territory & postcode)

have been invited to participate in a research project entitled: *Understanding how people with schizophrenia view influenza - a qualitative study*

Principal Investigator: Dr Paul Maguire The Canberra Hospital (02) 62443500

In relation to this project I have read the patient information brochure and have been informed of the following points:

1. Approval has been given by both the ANU Human Research Ethics Committee and the ACT Health Human Research Ethics Committee for the ethical aspects of the research project.

2. The aim of the project is gain a better understanding of how people with schizophrenia perceive risks associated with influenza (both seasonal and pandemic), obtain information about it and how they view protective measures against it.

3. The results of this study may, or may not, be of direct benefit to me.

4. My involvement will consist of participating in an interview with the researcher in which he explores my views on influenza; I am aware that hand-written notes will be taken during this interview.

5. Should I develop a problem which I am concerned may be connected with my involvement in the project, I am aware that I may contact Dr Paul Maguire on the number above.

6. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the researcher, I am aware that I may contact the secretariat of the ACT Human Research Ethics Committee through contact details provided on the information sheet.

7. I am aware that I can withdraw from this project at any time or refuse to take part in it without affecting my medical care. I may cease my involvement in this project if I find the questions in some way upsetting for me and no longer want to participate.

8. Participation in this project will not result in any extra medical or hospital costs to me.

9. I understand that information I give in this project will be de-identified and reported in a general way with my involvement and identity not being revealed.

After considering all these points I accept the invitation to participate in this project.

Name: _____   Date: _____

(please print)

Signature: _____

Appendix 15

Qualitative Study: Thematic Analysis Data

Extracts with Initial Codes

Data extracts with initial codes applied

Data Extract	Initial Code
Interviewer David, have you ever had the flu and if you have were you very sick with it? **David** *I'm not really sure.* [Slightly quizzical facial expression] *I've had symptoms sometimes that seemed like the flu but I'm not sure that it was actually flu.*	Uncertainty of diagnosis
David *No. Umm, I generally try to deal with it with alternative treatments...* [Smiles] *Like ginger tea or Echinacea. My family I grew up in, always believed more in alternative treatments like ginger and Echinacea.*	Use of alternative medicine as protection against influenza
David *If I heard that there was a really serious flu going around, and I wanted to get information about it, I would go to an official Website* [Confident facial expression]. **Interviewer** All right. Can I ask you why you would choose this as an information source? **David** *Yes, because they would know the latest information. And they would know what they are talking about* [Stated emphatically]	Importance of trust in information source
Interviewer David, sometimes there are flus called pandemics, which start overseas and spread around the world affecting large numbers of people; there was one in 2009 called swine flu which came to Australia. Do you remember hearing about it? And can you recall how you heard about it? **David** *Yeah...I remember it. I heard about it on TV...*	Television as information source on flu
David [referring to 2009 swine flu pandemic] *And I think it was blown out of proportion by the media.*	Exaggeration by media in reporting of influenza outbreaks
David *Yeah... if it was a serious flu I would be willing to be vaccinated, if one was available. But not for a weak flu, like swine flu was. It wouldn't be worth it.*	Realization that pandemic influenza not necessarily more virulent than seasonal influenza

Data extracts with initial codes applied (continued)

Data Extract	Initial Code
David [in reference to 2009 swine flu] *...but later I heard on TV that it was not even as bad as normal flu.*	Realization that pandemic influenza is not necessarily more virulent than seasonal influenza
David *But I'd definitely stay at home if I caught a bad flu. People at work don't appreciate it if you give the virus to them. That's not responsible* [Said emphatically]. *And the flu will last longer if you go to work instead of resting at home.*	Workplace and influenza
Interviewer Can I ask you why you think you would be less likely than others to catch it and also why you don't think it would be serious for you if you did catch it? **David** *Because I eat healthily, and try to keep pretty healthy*	General health factors as protective against influenza
Interviewer OK, and can I ask you what are your thoughts generally on things you can do to try to avoid catching it? **David** *Diet is important. Eating plenty of vegetables.*	General health factors as protective against influenza
David *Hand washing definitely* [Stated emphatically].	Hand washing viewed as effective protective measure against influenza
David *Umm...and covering your nose when sneezing* [Places right hand near nose]	Observing sneeze/cough etiquette to reduce spread of influenza virus
David *I probably wouldn't want to wear a face mask. I don't think they do much good, do they?*	Reluctance to wear face mask
David *Yeah.....if it was a serious flu I would be willing to be vaccinated, if one was available. But not for a weak flu, like swine flu was. It wouldn't be worth it.*	Willingness to have vaccination dependent on whether prevailing influenza is 'serious' or not

Data extracts with initial codes (continued)

Data Extract	Initial Code
David [in reference to future pandemics, including possible bird flu] *With future pandemics I guess I'd just keep my eyes open and deal with it on a case-by-case basis. See what information comes through on the official website - how serious it is, how quickly it is spreading, what I should do.*	Risk perception/willingness to adopt protective measures during future pandemic depends on incoming information at the time
Interviewer OK. And David what information about flus in general do you think it is important for people to know? **David** *Well, a few things I guess. The severity of the particular strain of flu. How close it is to our community. And how fast it is spreading. Umm...yeah they are the important things.*	Severity of strain is important information for people to know about a prevailing influenza
David *And perhaps the government could produce a fact sheet and put this up in places like GP surgeries or public places.*	Provision of information on influenza for public - seen as important
Interviewer Angus, if you wanted to find out more information about a flu going around, or influenza in general, how would you go about this? **Angus** *I'd ask my GP*	Roles for GP
Angus [in context of question on protective measures] *No one has talked to me. Most important thing is not to get too close to people in the bus.*	Avoidance of exposure to virus is important protective measure
Angus *I'd be willing to have one if my GP told me to get it.*	Trust in GP
Angus *Bird flu. Yes, heard about it on TV. Sounds serious but I'd be worried that they were bunging it on. You know, just making a story out of it.*	Exaggeration by media in reporting of influenza outbreaks

Data extracts with initial codes applied (continued)

Data Extract	Initial Code
Angus [referring to receiving a vaccination, seasonal or pandemic]] *I'd be willing to have one if my GP told me to get it*	Trust in GP
Angus *Would talk to my GP if it came to Australia and a lot of people were getting sick.*	Roles for GP Trust in GP
Angus *The main things would be ....*[Pause] *how serious the strain is....*	Severity of strain is important information for people to know about a prevailing influenza
Interviewer Did you try to find out more information about the flu on any of these occasions? **Alan** *No. My doctor told me what I needed to know*	Roles for GP
Interviewer Alan, can I ask you - if you wanted to find out more information about influenza in general - even if you were not sick at the time - how would you go about this? **Alan** *Speak to my GP.....*	Roles for GP
Alan [in response to enquiry whether anyone has spoken to him about protective measures against influenza] *Yeah, the nurse* **Interviewer** Which nurse are you referring to Alan? **Alan** *You know. The nurse at the practice ......At my GP's.*	Roles for GP
Alan *Pay attention to babies and very young people when there is a bad fly going around.*	Consideration of special groups during flu outbreaks

Data extracts with initial codes (continued)

Data Extract	Initial Code
Alan [in response to question on how to avoid contracting influenza] *Yeah, ummm.....spraying surfaces with Glen 20.*	Importance of general cleanliness in protecting against influenza
Interviewer OK. And Alan, can I ask you what are your thoughts generally on things you can do to try to avoid catching it? **Alan** *... And having lots of Vitamin C at the first sign that you could be catching it.*	Use of nutritional supplements as offering protection against influenza
Alan [when asked about risk perception regarding bird flu] *I'd only be concerned if the WHO was concerned*	Importance of trust in information source
Martin *Yeah....I'd reckon I've had about 4-5 episodes. Two really bad ones. Yeah when I thought I was dying.*	Influenza has the capacity to make you feel very sick
Martin [in context of question on risk perception about seasonal flu] *Yeah.. I've been getting it every year for the last few years. It's not too serious because I take Codral Cold and Flu tablets and stay in bed for 2-3 hours during the day.* **Interviewer** Can you describe to me how these help? **Martin** *Ummm....make you feel better till you get over it. Ay.*	Role for OTC (over the counter) symptomatic medication
Martin *Take time off to recover. Don't push yourself until you are well again. Yeah... generally take life easier. Ay*	Rest identified as important in the recovery from influenza
Martin [asked about ways to avoid catching the flu] Changing my bedclothes regularly. Um ...oh yeah - and having a drinking bottle that only I use. No one else uses [Facial expression of determination]. **Interviewer** How do these things work? **Martin** You don't get the germ that way, ay [Smiles].	Importance of general cleanliness/hygiene in protecting against influenza Avoiding exposure to virus

Data extracts with initial codes (continued)

Data Extract	Initial Code
Martin [in response to question about willingness to have vaccination for influenza, seasonal or pandemic] *Normally, I'm not that keen on needles, but I would trust my GP. If he reckoned I should get it I probably would.*	Trust in GP
Martin [in response to risk of pandemic bird flu] *No I don't think I'd be likely to get it. Probably wouldn't be too worried if I did. I would pray to God if I did get pretty sick with it [Looks upward].* **Interviewer** OK, and would you seek help in any other way? **Martin** *Probably go to my GP.*	Trust in GP Roles for GP
Martin [in response to anything else he thought was important about influenza] *Diet and exercise are important. Veges too.*	Importance of general health factors
Hugh [in response to being asked about past influenza experience] *Yes, once, when I was 15. I was pretty sick with it - vomiting [Frowns] and needed antibiotics.*	Influenza has the capacity to make you feel very sick
Interviewer [in the context of seeking information about influenza] Would you consider talking with your GP? **Hugh** *Ummm [Wry smile]......I don't really see a GP that much.*	Roles for GP (negative response)
Hugh *Yes. I heard about it from a teacher at school.*	School playing a role in information delivery about influenza
Interviewer OK. Hugh, people talk about it being helpful during flu outbreaks to wash your hands thoroughly, wear a face mask or to keep away from others - has anyone talked to you about this kind of thing. What do you think and feel about these things? **Hugh** *No. None one has talked to me about that. But I watched a training video at Woollies on it.*	Work and influenza

Data extracts with initial codes (continued)

Data Extract	Initial Code
Nigel *Yes. I had a bad flu about three months ago. Had to take time off work and go to bed. It lasted about two weeks*	Influenza has the capacity to make you feel very sick
Nigel [in context of being asked why it had been helpful to see GP] *To make sure I was going to get through it OK.* **Interviewer** Did your doctor provide you with helpful information about that flu? **Nigel** *Yes.*	Roles of GP
Nigel *Umm.....I don't mean spoke to me face to face, I mean that you see this sort of stuff on posters around the place. Like at the doctors.*	Posters as information source
Interviewer What are your thoughts generally on things you can do to try to avoid catching it? **Nigel** *Well, like I said before, I have the vaccine every year. I also take Bio C tablets and garlic tablets if there if a flu going around to ward it off.*	Alternative medicine as protection against influenza Nutritional supplements as protection against influenza
Nigel *Yeah... if it was a serious flu I would be willing to be vaccinated against it, if one was available. But not for a weak flu, like the swine flu was. It wouldn't be worth it.*	Willingness to have vaccination dependent on whether prevailing influenza is 'serious' or not
Nigel *Wash your hands and keep away from people with it* [Stated confidently].	Hand washing unequivocally viewed as effective protective measure against influenza

Data extracts with initial codes (continued)

Data Extract	Initial Code
Interviewer Amy, have you ever had the flu and if you have were you very sick with it? **Amy** *I don't think I've ever had a flu. I've had colds but the flu is worse isn't it? People almost feel like they're dying don't they when they get the flu?*	Differentiation between a 'cold' and 'the flu' Influenza has the capacity to make you feel very sick
Amy *I catch the bus so maybe it is more likely for me to catch flus. But mum gives me anti-stress hand wash, and I think this helps. And I try not to touch anything on the bus* [Pause]	Importance of general cleanliness / hygiene in protecting against influenza
Amy *Can you take an antibiotic for the flu?*	Role of medication in influenza
Interviewer Amy, what are your thoughts generally on things you can do to try to avoid catching it? **Amy** *I take horse radish and garlic. Oh, and fish oil tablets as well.*	Use of alternative medicine as protection against influenza Use of nutritional supplements in the protection against influenza
Amy *I would be happy to have the vaccination if my doctor thought it would be good to have it.*	Trust in GP
Amy [in context of protective behaviours] *.....I know that keeping hygienic is the best way. .....Staying hygienic is very important. I always try to keep my hands clean.*	General cleanliness / hygiene is important Hand washing viewed as important protective measure against influenza
Amy *I worry more about catching Hep B and C from public transport than bird flu, but I try to keep hygienic.*	General cleanliness / hygiene is important

Data Extract	Initial Code
Interviewer Amy, have you ever had the flu and if you have were you very sick with it? **Amy** *I don't think I've ever had a flu. I've had colds but the flu is worse isn't it? People almost feel like they're dying don't they when they get the flu?*	Differentiation between a 'cold' and 'the flu' Influenza has the capacity to make you feel very sick
Amy *I catch the bus so maybe it is more likely for me to catch flus. But mum gives me anti-stress hand wash, and I think this helps. And I try not to touch anything on the bus* [Pause]	Importance of general cleanliness / hygiene in protecting against influenza
Amy *Can you take an antibiotic for the flu?*	Role of medication in influenza
Interviewer .....Amy, what are your thoughts generally on things you can do to try to avoid catching it? **Amy** *I take horse radish and garlic. Oh, and fish oil tablets as well.*	Use of alternative medicine as protection against influenza Use of nutritional supplements in the protection against influenza
Amy *I would be happy to have the vaccination if my doctor thought it would be good to have it.*	Trust in GP
Amy [in context of protective behaviours] *.....I know that keeping hygienic is the best way. .....Staying hygienic is very important. I always try to keep my hands clean.*	General cleanliness / hygiene is important Hand washing viewed as important protective measure against influenza
Amy *I worry more about catching Hep B and C from public transport than bird flu, but I try to keep hygienic.*	General cleanliness / hygiene is important

Data extracts with initial codes (continued)

Data Extract	Initial Code
Samantha [in context of protective measures against influenza, seasonal or pandemic] *I would have a vaccine if my doctor recommended it, but I wouldn't have it as a routine measure. Only if it was necessary.*	Not willing to have vaccine as a routine measure
Samantha *... I probably wouldn't catch it because I don't go to airports where these viruses come in.*	Risk of contracting pandemic influenza associated airports / travellers
Samantha *That it can be passed from human to human by droplets. Hence the need to regularly wash your hands. Also not to cough in front of people. And to invest in cold and flu tablets. They cost about $12 for 24. Rest. Rest is important - if you've got the flu you should rest for a few hours during the day as well as at night. Oh, and you should take time off work to rest and to not spread the flu to everyone else.*	Hand washing clearly viewed as important protective against flu Cough etiquette viewed as important Role of regular medication Rest important during flu illness Work and flu
Samantha *How can you pick a cold from the flu. That's important. Flu lasts a lot longer and you are sicker. The cough can last for five and a half weeks.*	Differentiation between a 'cold' and 'the flu'
Samantha *It is important for the policy to ask people over 65 if they have had a vaccination.*	Need to protect specific groups
Amy *I worry more about catching Hep B and C from public transport than bird flu, but I try to keep hygienic.*	General cleanliness / hygiene is important

Data extracts with initial codes (continued)

Data Extract	Initial Code
Marnie *Yes, probably once. Twenty-two years ago when my son was two. I remember sweating so much and feeling terrible* [Frowns]. *I think I had the flu.*	Influenza has capacity to make you feel very sick
Interviewer Do you think he [*GP*] helped you to get better? **Marnie** *Yes. He did a physical checkup.*	Roles for GP (check-up)
Interviewer ....if you wanted to find out more information about a flu that was going or about influenza in general, how would you go about doing this? **Marnie** *.....Or I would talk to my doctor.*	Roles for GP (provide information on influenza)
Marnie [during discussion of seasonal influenza] *Also I won't let anyone into my house who has dogs. They carry a lot of germs. Their owners don't wash their hands properly* [Looks slightly annoyed]. *It's true.*	Importance of general cleanliness /hygiene in protecting against influenza Hand washing clearly viewed as important protective against flu
Marnie *Washing ya hands. Yeah that's important* [stated confidently]. *No one has talked to me about these things but it is taught in school isn't it? I wash me clothes often too, especially me jacket. It can get really dirty and carry germs. People can touch things that can then get on to ya clothes. I don't like masks, you can't breathe properly with them on, but they can stop you breathing in dirt.*	Hand washing clearly viewed as important protective against flu Importance of general cleanliness /hygiene in protecting against influenza Reluctance to wear face
Marnie *I don't believe in them for myself. But people doing the garbage need to be immunized.*	Need to protect specific groups

Data extracts with initial codes (continued)

Data Extract	Initial Code
Ronda *Yes. I get about three flus in every ten years. The last one was about four years ago. Was pretty sick with it. Felt really tired and exhausted.*	Influenza has the capacity to make you feel very sick
Interviewer Did you try to find out more information about the flu on these occasions? **Ronda** *No, I didn't need to. My GP checked me and told me what I should do. Mainly just rest and take it easy.*	Roles for GP (check-up, provide information) Rest important during flu illness
Ronda [in response to question about hand washing, wearing a face mask and social distancing / isolation *Not really. No. No one has talked to me about these things. They may not help that much. If you didn't do these sort of things and got the flu, then you were going to get it anyway, and it wouldn't have helped you even if you had done those things. It's your immune system that matters.*	Immune system more important than protective behaviours
Ronda *Look after yourself. Take care of yourself generally. That will keep your immune system working properly. That's what really matters* [Said emphatically]. .	Importance of general health factors as protection against influenza
Ronda *Bird flu. I've heard of it. On the TV news and on the radio too. Yeah..I would be worried if it came to Australia. I would be worried that I could catch it. I've heard that it is very serious. Ten times worse than normal flu. So it could be serious for me if I caught it but it's hard to know because the media always exaggerates things.*	Tendency of media to exaggerate reporting of influenza outbreaks
Amy *I worry more about catching Hep B and C from public transport than bird flu, but I try to keep hygienic.*	General cleanliness / hygiene is important
Ronda *Umm...How do you tell the difference between a cold and the flu?* **Interviewer** Why do you think that is important? **Ronda** *Because a cold is not serious but the flu can be.*	Differentiation between a 'cold' and 'the flu'

Data extracts with initial codes (continued)

Data Extract	Initial Code
Tina *I very rarely get the flu but I was very sick with flu last year. Had to spend ten days in bed.*	Influenza has capacity to make you feel very sick
Interviewer In what way? **Tina** *To make sure I was going to be OK.*	Roles for GP (check-up)
Interviewer If you wanted to find out more about a flu that was "going around" or about influenza in general, how would you go about this? **Tina** *Ask a doctor. Or my brother. He is a microbiologist.*	Roles for GP (provide information on influenza) Family as health information source
Interviewer Did you think you might get it? And what did you think and feel about this pandemic flu? **Tina** *No, I wasn't worried about getting it because I hadn't been overseas and wasn't around anyone who had been overseas.*	Risk of contracting pandemic influenza associated airports / travellers
Interviewer What are your thoughts generally on things you can do to try to avoid catching it? **Tina** *Wear extra layers to bed at night. Wear warm clothes when it is cold. Listen to the weather forecast and stay in-doors if it is going to rain and be cold.* **Interviewer** So in your view, keeping warm and avoiding getting cold or wet, can help protect against the flu. **Tina** *Yes*	General lifestyle factors viewed as important in protection against influenza
Tina [in context of possible future pandemic, including bird flu] *No, I don't worry about this. I haven't heard of bird flu but hopefully there would be an antibiotic against it or a flu vaccine for it. If it was thought to be serious I would take antibiotics or have the vaccination.*	Regular medication for influenza

Data extracts with initial codes (continued)

Data Extract	Initial Code
Interviewer OK and what information about flus in general do you think it is important for people to know? **Tina** *..... And whether it is terminal as a disease.*	Important to know about the severity of the viral strain
Interviewer Is there anything else about influenza you feel is important or that you would like to tell me that I haven't asked about? **Tina** *It would be important to know how long the strain would affect you for.*	Important to know about the severity of the viral strain

Appendix 16

Qualitative Study: Thematic Analysis

Working List of Codes

<u>Working List of Codes</u>

1. Uncertainty of diagnosis

2. Use of alternative medicine as protection against flu

3. Importance of trust in information source

4. Television as prominent information source on influenza

5. Exaggeration by media when reporting influenza outbreaks

6. Realization that pandemic influenza not necessarily more virulent than seasonal influenza

7. Work place and influenza

8. General health factors as protective against influenza

9. Hand washing viewed as important protective measure against catching influenza

10. Sneeze / cough etiquette important in reducing spread of influenza

11. Reluctance to wear face mask as protective factor

12. Risk perception/willingness to adopt protective measures during future pandemic depends on incoming information at the time

13. Severity of strain is important information to know about a prevailing influenza

14. Provision of information on influenza for public seen as important

15. Roles for GP (info source, check-up, nurse)

16. Avoidance of exposure to virus is important protective measure

17. Trust in GP

18. Consideration of specific groups during flu outbreak

19. Importance of general cleanliness in protecting against influenza

20. Use of nutritional supplements as providing protection

21. Importance of trust in information source

22. Influenza has the capacity to make you feel very sick

23. Role for OTC symptomatic medication

24. Rest identified as important in the recovery from influenza

25. School playing a role in the delivery of information about influenza

26. Posters as information source

27. Willingness to have vaccination dependent on whether prevailing influenza is "serious" or not

28. Importance of being able to differentiate between a "cold" and "the flu"

29. Role of regular medication for influenza

30. Risk of contracting pandemic influenza is associated with airports, travelling or mixing with travellers

31. Amount of worry related to "how strong" the virus is

32. Not willing to have vaccination as a "routine measure"