

# 1 OVERVIEW, BACKGROUND, AIMS AND METHODOLOGY

## 1.1 Setting the scene

The first survey of people living with psychotic illness was conducted in 1997-98 and provided a picture, for the first time, of the severe impact of these illnesses in Australia. In 2010 a second national survey of people with psychotic illness was undertaken to provide updated estimates of the number of people being treated for psychosis, and to determine who these people are, the health services they receive and the impact of these illnesses.

The second survey also allows us to examine how changes to public sector mental health services administered by state and territory governments in the intervening 12 years have impacted on people's lives. These are services that are the principal providers of care to people with psychotic illnesses. The reforms have been substantial, achieving a restructured service system characterised by substantial resource growth and a reorientation of the mix of services with a more community orientated focus.

## 1.2 Scope of the survey

The selected sample of the 2010 national survey comprised of 1,825 adults with psychotic illnesses aged 18-64 years in contact with public specialised mental health services between April 2009 and March 2010 inclusive, as well those receiving mental health services from government funded non-government organisations in March 2010. Two thirds of those in the sample were current clients of the public specialised mental health services, that is in March 2010.

The survey did not cover those people with psychotic illness who are treated only in the private sector by a private psychiatrist, psychologist or general practitioner. It also did not cover people who are currently experiencing a psychotic illness, but were not receiving any mental health services through either the public or private health systems.

The impact of these exclusions is twofold. Firstly, prevalence rates based on the survey sample are likely to underestimate the true prevalence of psychotic illness in the Australian population. The 1997-98 survey suggests that the inclusion of those being treated privately could increase estimates of the prevalence by an additional 25%-50%. Secondly, it did not capture those who have experienced an illness, received treatment previously and have recovered to the extent that they are not currently receiving treatment.

Given this, conclusions drawn from this survey on the clinical, social and economic outcomes are based on the group of people with psychotic illness who generally experience the most severe and persistent disorders.

## 1.3 Comparability with the first national survey of psychotic illness

The bulk of this report is focussed upon presenting the new evidence from the 2010 survey. For many, however, there is the question of how the lives of people with psychosis in 2010 compares with those prior to the significant changes in mental health service delivery. Comparisons with 1997-98 must be undertaken with caution. Nonetheless, in Chapter 19 there is an examination of the findings from each survey, comparing the data that can be compared on those who received public specialised mental health services. Prevalence estimates are also examined.

## **1.4 Report structure**

The report presents summary data from the second national survey of psychotic illness. Data is descriptive in nature. Future publications will provide additional information on key elements of the results and analyse these in more detail.

### **Prevalence**

Chapter 2 explores the one-month and twelve-month treated prevalence rates.

Further information is provided in Appendix 2.

### **Profiling psychotic illness**

Chapters 3 to 18 present the initial results of the second national survey of psychotic illness. Information is provided on a broad range of topics, with more detailed data available in the correspondingly numbered appendices.

Chapter 19 compares the results of the first survey undertaken in 1997-98 with the 2010 findings.

Chapter 20 provides a summary of the key findings from the survey.

### **Appendices**

Appendices 1-18 provide more detailed data on the results presented within the report. There is a corresponding appendix for each chapter.

Appendix 19 provides a description and technical information on the 1997-98 survey.

Appendix 20 contains detailed information on the oversight of the 2010 survey and contributors in development of the survey protocol and assessment instruments.

A glossary is provided at Appendix 21.

Appendix 22 contains references.

## **1.5 What is a psychotic illness?**

Psychotic disorders are a diverse group of illnesses that have their origins in abnormal brain function and are characterised by fundamental distortions of thinking, perception and emotional response. These disorders include, among others, schizophrenia, schizoaffective disorder, bipolar disorder and delusional disorder. The most common of these is schizophrenia.

The typical age of onset for many psychotic disorders, but especially schizophrenia, is in the late teens and early adulthood. Onset at this age has particularly detrimental consequences for affected people, disrupting a critical period for consolidation of life skills in terms of education, employment, adult relationships and community engagement.

The community cost of psychosis is also high. This cost is borne by all involved, not only in terms of the effects on the individual, their family, friends and carers, but also in terms of lost productivity and the cost of providing medical, mental health and other support services.

Among the psychoses, worldwide, schizophrenia and bipolar disorder rank in the top ten causes of disability. Together, these two disorders account for more than 5% of the total burden of disease-related disability. A little over a decade ago, the costs of psychosis in Australia were estimated to be an average of \$46,200 per patient per year, of which 40% was for mental health care and 60% was due to lost productivity. Schizophrenia accounted for the highest costs, amounting to at least \$1.44 billion of the total \$2.25 billion per year for psychosis in the Australian population.<sup>1</sup>

## 1.6 Aims

The 2010 national survey of psychosis, the “Survey of High Impact Psychosis (SHIP)”, was designed to collect data capturing the impact of psychosis across different age groups, with the capacity to examine outcomes by sex and diagnostic category. It is Australia’s second national psychosis survey. In 1997-98, the Low Prevalence (Psychotic) Disorders Study produced the first Australian epidemiological data on people with psychosis in contact with public sector mental health services, as well as data on those in treatment in the private sector and those not in contact with services, living in marginalised circumstances reliant on welfare agencies, soup kitchens and refuges.<sup>2,3</sup> The main aims of the 2010 survey were similar to those in 1997-98, that is to:

- **Estimate the treated prevalence of psychosis for people seen by public sector mental health services**

The survey has produced not only one-month prevalence estimates for those in contact with public specialised mental health services (inpatient, outpatient, ambulatory and community clinics), but also, for the first time, prevalence estimates for people with psychosis who had only been in contact with non-government organisations funded to support people with mental illnesses.

Estimates have also been made of the prevalence of psychotic illness and the numbers of Australians experiencing these disorders who are receiving publicly funded mental health services in a 12-month period.

- **Describe the profile of people with a psychotic illness including personal, social and living circumstances, their mental and physical health and cognition**

The survey provides basic demographics on users of publicly funded mental health services who have psychotic illness and the age at which they first experienced symptoms. It collected data on the degree to which participants’ basic requirements for adequate housing, food, employment and money were met and provides information on their family structure, and children and others for whom they care. It also collected information on smoking, alcohol and drug use, levels of exercise, physical health, metabolic measures including blood glucose and lipid profiles, and cognitive and other functioning.

- **Determine the use of services by people with psychotic illness**

Data were collected on participants’ use of mental health services, emergency attendance and hospital admissions, the extent to which they were supported by case workers, their involvement with non-government organisations and services provided by general practitioners. It also documented the quality of their contact with service providers.

Information on medications for both mental and physical conditions was collected.

- **Assess the impact of psychotic illness and identify factors related to better outcomes**

Information on the lives of public sector mental health consumers with psychosis, their social isolation, functioning, support received and daily circumstances were collected to enable a comprehensive analysis of factors associated with both poorer and better outcomes.

## 1.7 Who the survey covered

The survey covered adults with psychotic illnesses aged 18-64 years in contact with public specialised mental health services in seven selected catchment sites around Australia.

The survey sample comprised:

- people in contact with public specialised mental health services in March 2010;
- people who used public specialised mental health services in 11 months prior to March 2010, that is from April 2009 to February 2010; and
- people in contact with non-government organisations funded to support people with mental illnesses in the March 2010 census month.

The survey did not enumerate certain groups of people:

- those under the age of 18 years or those over the age of 64 years;
- those who did not make contact with public specialised mental health services within the selected 12-month period or non-government organisations funded to support people with mental illnesses in the census month;
- those who, in the census month, were solely in contact with general practitioners or private psychiatrists and psychologists; and
- those who were homeless and not in contact with any services.

From this population an interview sample was selected on the basis of a number of factors. These included the following:

- Participants required positive ratings for at least two of the items on the screening instrument. These items covered hallucinations and delusions (six items), and being on antipsychotic medication (key worker form) or told by a doctor that they had a psychotic disorder (participant form).
- Alternatively, they were eligible if they had a recorded diagnosis of psychosis in the 11 months prior to census. Transient psychotic disorders related to acute substance intoxication or withdrawal are not the focus of the current survey. However, a case of psychosis may be missed if the primary diagnosis at the time of an inpatient admission is a substance-induced psychosis masking an underlying psychotic disorder. For this reason, administrative registers for the 11 months prior to the census month were scanned for people with at least two inpatient admissions with a diagnosis of substance-induced psychosis.

All cases were assessed against diagnostic criteria at interview and allocated an ICD-10 diagnosis.

## 1.8 Methodology

The survey samples were drawn from seven catchment sites across five states of Australia: New South Wales (Hunter, New England; Orange), Queensland (West Moreton), South Australia (Northern), Victoria (North West; St Vincent's) and Western Australia (Fremantle, Peel and Rockingham Kwinana). The sites were selected to be broadly representative of public specialised mental health services administered by states and territories.

In total, site catchments covered 61,682 square kilometres and an estimated resident population aged 18-64 years of 1,464,923 people, or approximately 10% of the Australian population aged 18-64 years.

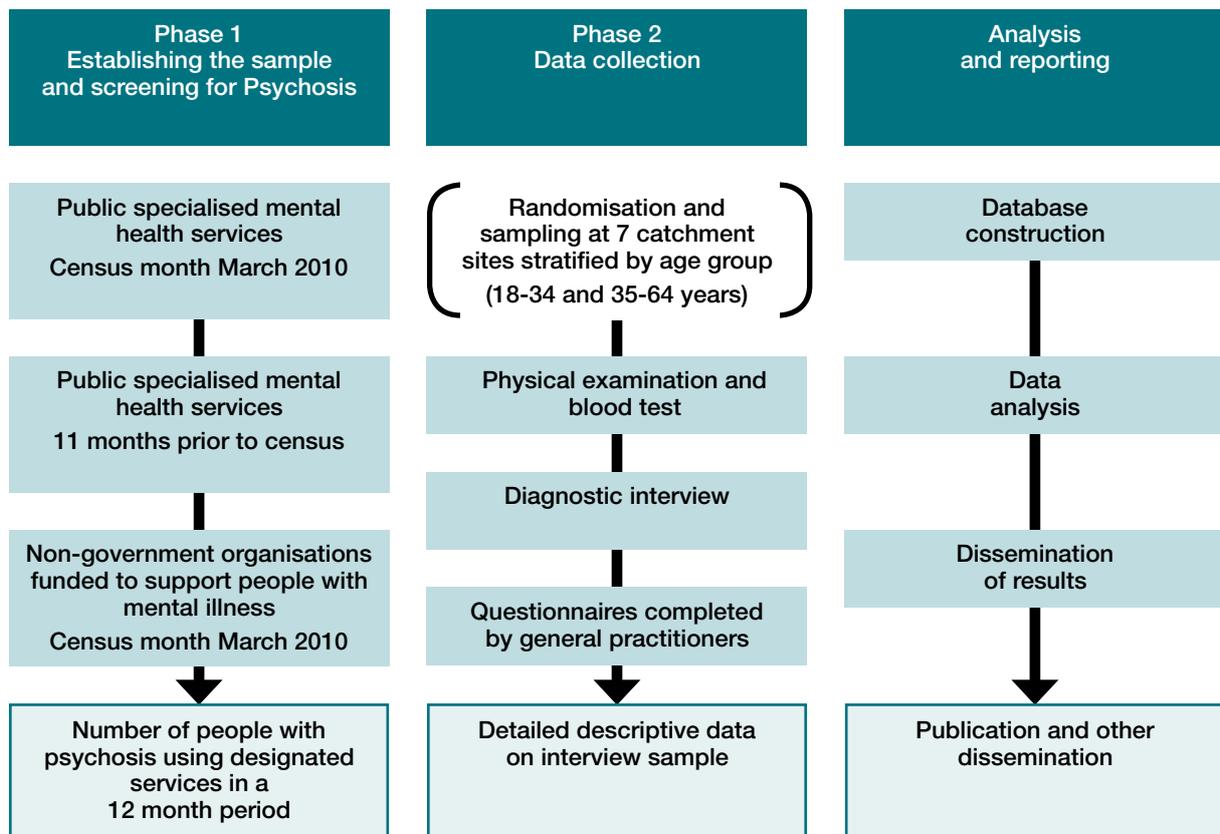
Further information on the catchments is provided in Appendix 20.

### 1.8.1 Two-phase design

A two-phase design, especially suited for uncommon disorders, was employed. Firstly the sample is established, followed by the second phase of data collection (Figure 1-1).

**Figure 1-1. Conduct of the survey and reporting**

**Australian National Survey of Psychosis 2010**



Phase 1 screening in a selected census month, March 2010, identified all people resident in the survey catchment sites and in contact with public specialised mental health services.

Screening also took place in government funded non-government organisations that provided mental health services in each of the catchment sites. This provided additional information on people only receiving services from these agencies in the census month.

A psychosis screener was used to identify individuals likely to meet criteria for formal diagnosis. This brief assessment tool was developed for use in the first survey and further refined for this survey.

In addition, administrative records were scanned to identify people with a recorded diagnosis of psychosis and in contact with public specialised mental health services in the 11 months prior to, but not in, the census month.

In Phase 2, information was collected on those who screened positive for psychosis and a smaller number of those who screened negative.

Separate recruitment targets were set for each catchment site and for the younger (18 to 34 years) and older (35 to 64 years) age groups. Age stratification was a key element in the survey design, as it ensured better coverage of both age groups, which are very differently affected by psychotic illness.

Interviewing took place between April and December 2010, except in Orange where interviewing continued through to the end of March 2011.

At interview, participants were asked to provide consent for their general practitioner to be contacted. These general practitioners were then asked to complete a questionnaire providing information on the participant, as well as a second questionnaire on their perspectives on the treatment and management of psychosis in general medical practices.

## 1.9 Instruments and assessments

In the development of the survey interview and assessment modules, particular importance was placed on the use of measures that were reliable, available, and cost and time effective. Minor enhancements only were made to the survey used in 1997-98 to ensure comparability with this survey and to enable an assessment of change over time. Additional material was included to allow comparison with other Australian data collections. These included the 2007 National Survey of Mental Health and Wellbeing and Australian Bureau of Statistics national surveys. This facilitated comparison with population norms.

The 32 modules of the survey covered:

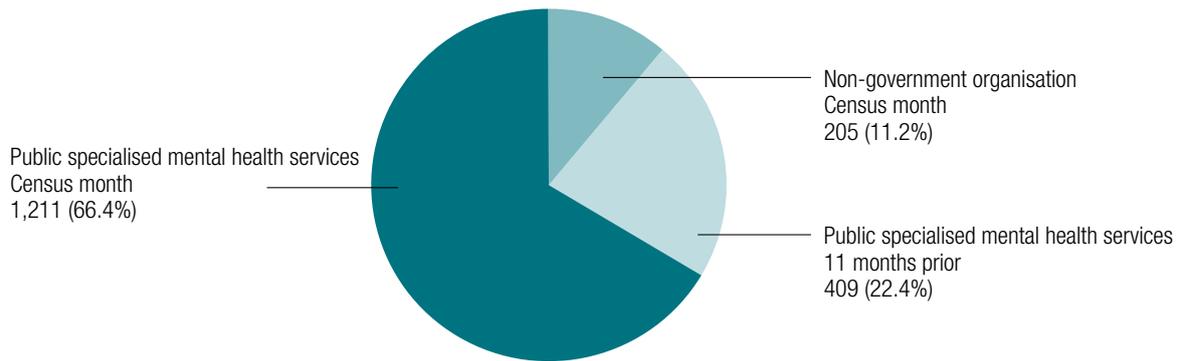
- **Demographics:** age and sex; education; housing and homelessness; employment; finances; children and other caring responsibilities; childhood experiences; victimisation and offending; and personal safety
- **Physical health:** nutrition; physical activity; physical health and metabolic measures; smoking and alcohol and drug use
- **Social participation and functioning:** satisfaction with life, ability to perform activities of daily living; and global functioning ratings
- **Quality of life**
- **Clinical diagnosis and symptoms:** ICD-10 diagnosis, symptoms associated with psychosis, anxiety, obsessions and depression
- **Course of illness and age of onset**
- **General cognitive ability**
- **Service use and treatment:** use of inpatient, emergency, outpatient, public community mental health, community rehabilitation and day therapy, general practice and non-government organisation services; case worker contact; use of employment, housing, family and other human service providers; medication use and its side effects; and use of psychosocial therapies
- **Perceived need for services:** met and unmet need for mental health and other services

Participants were asked to undertake a physical examination in which their blood pressure, height, weight and waist circumference were measured. Participants were also asked to provide a fasting blood sample so that their high density lipoproteins, triglycerides and plasma glucose levels could be determined.

## 1.10 Interview sample selection

A total of 7,955 people were screened positive for psychosis across the seven catchment sites. Of these, a sample of 1,825 participants were randomly selected for interview in two age groups (18-34 and 35-64 years).

Two thirds of the interviewed participants (66.4%) had been in contact with public specialised mental health treatment services in the census month. In the same month, a further 11.2% had only been in contact with non-government organisations funded to support people with mental illnesses. An additional 22.4% had not been in contact with designated services in the census month, but had been in contact with public specialised mental health services in the 11 months prior to census (Figure 1-2).

**Figure 1-2. Sector in which interviewed participants were identified**

An additional 164 people were randomly selected for interview from the pool of people who were screened negative for psychosis. This group completed the diagnostic module only. Their data enabled estimation of prevalence in the census groups without assuming that the psychosis screen had perfect sensitivity.

Comparison of participant screening data with data for those selected for interview, but not participating, indicates no systematic selection biases. Accordingly, the selected sample is broadly representative of adults with psychosis aged 18-64 years and in contact with public specialised mental health services and non-government organisations supporting people with mental illnesses.

