

People Living with Psychotic Illness: An Australian Study 1997–98

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Foreword

This national study of people living with psychotic disorders coordinated by The University of Western Australia is part of the National Survey of Mental Health and Wellbeing, a major epidemiological study of international significance.

The study of people living with psychotic illness was undertaken as one of the three components of the National Survey of Mental Health and Wellbeing that was established by the Commonwealth Department of Health and Aged Care in 1995 to provide information representative of the mental health status and needs of the entire Australian population. The household study of adult Australians undertaken by the Australian Bureau of Statistics is completed and the Child and Adolescent Survey being undertaken through the University of Adelaide on behalf of the National Collaborating Centres for the Survey of Mental Health and Young People is close to completion.

Much has been achieved through the National Mental Health Strategy. The past has been confronted and today we are more knowledgeable and less fearful of schizophrenia and other psychotic disorders. People with psychotic disorders are accessing mental health services and are regularly in contact with general practitioners, however, they can be isolated in Australian society. They are marginalised not only by the nature of their illnesses, but also by society's reaction to the impairments and behaviours that result from the disorders.

Psychotic disorders cover a diverse group of illnesses that are characterised by fundamental distortions of thinking, perception or emotional response and include schizophrenia, bipolar affective disorders and delusional disorders.

The report presents the main findings gathered through a census of 3,800 Australians aged 18-64 years of age with psychotic disorders. They were drawn from people who attended mental health services in catchment areas in the Australian Capital Territory, Queensland, Victoria and Western Australia. In addition an in-depth interview was conducted with 980 of the respondents.

From the study we have attained a lot of important information that will guide policy and programs. These include the fact that between 4 and 7 persons per 1,000 adults resident in urban areas are in contact with mental health services during any given month because of symptoms of psychotic disorder. The majority of psychotic illnesses begin in early adulthood. Schizophrenia and schizoaffective disorders account for over 60% of the prevalence and men and women are equally affected. For a high proportion of survey participants the course of the illness had been continuous without remission for an average of 15 years after the first onset of psychotic symptoms.

The study clearly identifies the fact that psychotic disorders represent a major public health challenge in Australia today. It highlights the high burden of ill-health and disability experienced by people with psychotic disorders throughout their lives. Only a minority of people had attained a level of functioning and wellbeing that is commensurate with a good quality of life. The impact of psychotic disorders is experienced in terms of symptoms (duration and distress), compromised daily living and life achievement activities (particularly in relation to education and employment) and dependency as a consumer of welfare and support services. The additional impact on the homeless is further cause for concern.

This report highlights the need to come together to strengthen partnerships across all service providers, particularly to better provide accessible and flexible accommodation, employment, legal aid services, vocational training and community-based rehabilitation services, for this disadvantaged group in the community. More importantly, it stresses the need for continued efforts by all Australians to lessen the suffering, particularly the pain of rejection of those with mental illness, so that all Australians enjoy the high quality of life we have in this country.

I would like to acknowledge and thank the Technical Advisory Committee, Low Prevalence Disorders Study Group and the Project Teams for their work and contribution overseeing this important initiative.

A handwritten signature in black ink that reads "Michael Wooldridge". The signature is written in a cursive, flowing style.

Dr Michael Wooldridge

October 1999

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* A full listing of all individuals who participated in this study is given in Table 3.1 on page 6.

We are grateful to the many people with psychotic disorders who participated in this study. In addition, the investigators wish to express their gratitude to the hundreds of mental health professionals around Australia who assisted with the preparation and operation of the survey.

Abstract

The point prevalence (one month) of psychotic disorders in the adult population of predominantly urban areas in Australia is in the range of 4 to 7 per 1000 with a weighted mean of 4.7 per 1000. People with psychotic disorders tolerate profound and widespread disability, decreased quality of life, persistent and distressing symptoms, and frequent side-effects of medication. While many people with psychotic disorder receive their care in the community, the data suggest that in many respects this care is suboptimal and a number of health and disability-related needs remain unmet. The study highlights the resilience of people with psychotic disorder in their coping with multiple handicaps and provides a challenge to the community to help improve outcomes for this disadvantaged group.

Executive summary

Background

The Commonwealth and State Governments have recognised the need to improve services for people with mental illness. As such, the National Survey of Mental Health and Wellbeing was commissioned by the Commonwealth Department of Health and Aged Care. This report presents details of one part of the overall survey, and was designed to provide epidemiological, clinical and social data related to the needs of people with psychotic disorders.

Psychotic disorders are a diverse group of illnesses that impact on aspects of brain functioning involved in thinking, perceptions, emotions and communication. As a result, affected individuals can ‘lose touch with reality’. Psychotic disorders include schizophrenia and related disorders, bipolar affective disorder, depression with psychotic features, delusional disorders and acute transient psychotic disorders. The main symptoms are:

- Delusions (incorrect beliefs out of keeping with shared beliefs and values in the culture)
- Hallucinations (perceptions without stimuli, for example, hearing voices)
- Disorganised communication (difficulty in understanding other people, in pursuing a logical train of thought and in expressing thoughts and feelings in speech and ‘body language’)
- Lack of motivation and planning ability
- Mood swings

Aims

A survey of individuals with psychotic disorders was considered essential because psychotic disorders:

- often start in early adulthood, and tend to have a prolonged course (often life-long)
- cause significant distress to affected individuals and their families
- are associated with significant disablement and increased suicide rates
- are managed by means of suboptimal treatments, with many individuals persistently symptomatic, burdened with side effects of the medication and prone to relapse
- need co-ordinated community, rehabilitation, in-patient and emergency services
- contribute disproportionately to individual and family suffering, and provide a challenge to service providers.

The study aimed to:

- establish reliable one month and one year prevalence estimates of psychotic disorders amongst adults aged 18 to 65 years, in Australia
- determine treated prevalence and give an estimate of those individuals with psychotic disorders no longer in contact with mental health services

- establish the demographic profile of individuals with psychotic disorders, including age and sex distribution, ethnicity and country of birth
- quantify the rates of disablement associated with psychotic disorders
- determine service utilisation by individuals with psychotic disorders
- provide an estimate of unmet need for individuals with psychotic disorders

This is the first study of its kind conducted in Australia and one of the few worldwide that have set such goals and utilised a similar design.

Key features of the study

- Four ‘catchment’ areas were defined: the Australian Capital Territory; four of the 39 Queensland Health Districts including part of the City of Brisbane; the inner eastern part of Melbourne, Victoria ; and the inner city, inner northern and south-eastern districts of Perth, Western Australia.
- A systematic one month census of key sites (for example, hospitals, community clinics) within each catchment area was undertaken in order to identify all people who were likely to have psychotic disorders according to the screening criteria.
- Other relevant service providers and agencies were targeted in each catchment area in order to identify people with likely psychotic disorders. These included general practitioners, private psychiatrists, hostels, boarding houses, rehabilitation sites, homeless and emergency shelters, church and community organisations.
- A random sample of all individuals who were screen-positive (and an additional, smaller sample of persons who were screen-negative) were invited to participate in a comprehensive interview about symptoms, level of disability, service utilisation and unmet need.

All individuals in contact with ‘mainstream’ mental health services (including in-patient units, community clinics, outpatient departments) during a census month were systematically screened with an instrument (Psychosis Screen) specifically designed for this study. All general practitioners and private psychiatrists in the four catchment areas were approached and invited to participate in the study; those agreeing to participate completed the Psychosis Screen on individuals they had seen during the census month who they believed had a psychotic illness. A comprehensive list of agencies known to provide care to individuals with psychosis in the catchment area was compiled (for example, hostels, boarding houses, drop-in centres, refuges and shelters); the Psychosis Screen was then completed on a sample of consenting residents at those locations by interviewers.

To be eligible for the study, criteria related to age (18-64 years) and postcode (within the catchment areas) had to be met. Eligible individuals identified at screening as ‘probably psychotic’ were randomly selected for inclusion in the interview phase of the study. In order to better describe the needs of individuals with psychotic illnesses who were not in contact with ‘mainstream’ services during the census month, separate protocols were used.

A new instrument was designed specifically for this study, the Diagnostic Interview for Psychosis (DIP). The DIP, a semi-structured interview to be administered by trained clinical staff, consists of three main segments:

- *Demographic variables* (age, gender, ethnicity, country of birth, etc.), socio-economic descriptors (such as accommodation and finances), and disability items (covering participation in occupation, study, household activities; relationships and social network; activities of daily living; and interests).
- *Symptoms* commonly found in psychoses were assessed at interview over three time periods (past month, previous year, and 'lifetime-ever'). The scores on symptoms were linked to a computer program that generates several of the main diagnostic criteria currently in use, such as the International Classification of Diseases, Tenth Revision (ICD-10) and the American Psychiatric Association's Diagnostic and Statistical Manual, Third Edition, Revised (DSM-III-R).
- *Patterns of service utilisation* over the past year were examined. Areas inquired about include: in-patient treatment; emergency department attendance; community treatment; outpatient treatment; rehabilitation and day programmes; health and welfare agencies; non-government organisations; and general practitioner and private sector mental health contacts. Respondents are also asked about perceived unmet need. Current medication, including side effects thereof, is also included.

Nine hundred and eighty people with likely psychotic disorders were randomly selected from among those identified in the census month. These 980 individuals were interviewed and form the basis of this report. In keeping with the move to community-based care, 43 per cent of the census month participants were identified via community clinics and outpatient departments, and 27 per cent via inpatient wards. Private psychiatrists and general practitioners contributed sizeable proportions of respondents (9 per cent each). Twelve per cent of the participants were recruited via hostels, shelters for the homeless and other 'marginal' sites. Over 40 per cent of the interviews were conducted in the respondent's home. Males outnumbered females in the study (1.5: 1). Over one third of participants were aged less than 35.

A further 146 individuals identified as being in contact with services within three years of the census month but not in the census month were interviewed, bringing the total number of participants to 1126. The results for these additional 146 individuals are given separately in Section 18.4.

The results

- The prevalence of psychotic disorders in the adult population of urban areas in Australia is in the range of 4 to 7 per 1000 depending on the catchment area. Schizophrenia and schizoaffective disorders account for over 60 per cent of the prevalence.
- People with persisting or recurrent psychotic disorders carry a heavy burden of ill-health and disablement. The proportion of participants with obvious or severe dysfunction in important areas of daily living was high: overall 29.8% showed obvious or severe dysfunction in their ability to care for themselves, 59.1% in their overall socialising, 57.6% in their social interactions, 39.1% in intimate relationships and 32.9% in sexual relationships. In addition, 46.3% of those engaged in paid work, study or home duties recorded obvious dysfunction in their work performance while 49.1% of those living in households recorded obvious dysfunction in their participation in household activities. One out of five parents with a caring role for their children were impaired in their performance of that role.

- The symptoms of psychotic disorders are distressing and tend to persist or re-occur over long periods of people's lives. Males and females are similarly affected.
- Co-morbid substance use disorder ('dual diagnosis') complicates the course of psychotic illness in a substantial proportion of cases; 30.0% reported a history of alcohol abuse, 25.1% a history of cannabis abuse and 13.2% a history of other substance abuse.
- A very high proportion of the people with persisting or recurrent psychotic disorders have lost essential life roles with 46.7% severely impaired in daily life. Social isolation is a major problem.
- Social and economic disadvantage often precedes the onset of psychosis.
- Unemployment and relative poverty are widespread among people with psychotic disorders. Experiences such as attempted suicide or self-inflicted harm during the past year (reported by 16.5% of those interviewed); feeling unsafe in one's locality (15.3%); being the victim of violence (17.6%); or being arrested (10.2%) are examples of crises that aggravate the lives of many persons with psychotic disorders.
- Some people with psychotic disorders function well in spite of having symptoms and experience less disability. These high-functioning individuals tend to have a later onset of psychotic disorder, to have attained a good level of educational and occupational adjustment prior to onset, and are less likely to have a 'dual diagnosis' of substance use disorder, including alcohol and drug abuse.
- The majority of people with psychotic illnesses describe objectively poor quality of life. Yet a high proportion are satisfied with life in general and the level of independence they have in particular.
- The majority of the participants in the study experience a high rate of both voluntary and involuntary hospital admissions per year (mean number of admissions 2). The majority of hospital admissions are brief (median 6 weeks) but 10% of the people with psychoses spend prolonged periods in hospital. This accounts for a mean length of stay of 13 weeks. There is a high utilisation of the general hospital and psychiatric emergency services by people with psychotic disorders.
- Community mental health services are widely used and more than one-half of the patients with psychoses have a case manager. However, the needs for counselling and support in daily living that many people with psychotic disorders identify are not adequately met.
- There is a general shortage of support services to people with psychotic disorders living in a variety of circumstances. This applies especially to the high proportion of people with psychoses who live in marginal accommodation without support.
- There is a serious lack of, and a need for, community-based rehabilitation programmes for people with psychotic disorders. Given the range of disabilities described, there is a need for better access to public housing and for residential disability support services linked to accommodation of various types.
- A high proportion of the people with psychoses are in contact with general practitioners.
- The great majority find anti-psychotic medication helpful in controlling their symptoms but feel significantly impaired in their daily lives by drug side effects.
- There is a high level of satisfaction with the social security services but less satisfaction with housing, employment and legal aid services.

- Non-governmental agencies and services including the churches, community charities and self-help groups are generally perceived as helpful.
- Many participants in this study expressed concerns about specific aspects of the current provision of mental health care; of those, access to treatment, continuity of care and the need for mental health information rank highest in the perception of the consumers.
- The study points to a need for a national programme of secondary prevention and disability reduction in people suffering from psychotic disorders. Among the many problems that need to be addressed by such a programme, two outstanding priorities that have been highlighted by the findings of this study are: (i) the reduction or prevention of substance abuse complicating the course and management of psychotic illnesses and (ii) the lack of adequate, community-based rehabilitation programmes.

1 Introduction

In 1995 the Commonwealth Department of Health and Family Services (HFS) initiated the National Survey of Mental Health and Wellbeing, a major survey involving data collection across Australia, and intended to enlarge and strengthen the evidence base supporting the National Mental Health Strategy. The plan for the survey envisaged three independent investigations: (i) a survey of a nationally representative sample of some 10,000 adults aged 18 years or over, focusing primarily on common mental disorders such as anxiety, depression, and substance use disorders¹; (ii) a survey of mental disorders and mental health problems among children and adolescents, based on a representative sample of schools across Australia; and (iii) an epidemiological and clinical study of low-prevalence disorders, including schizophrenia and mood disorders with psychotic features, in primarily urban areas in the Australian Capital Territory, Queensland, Victoria, and Western Australia.

The study was supported by a grant of the Commonwealth Department of Health and Family Services administered through The University of Western Australia. In Canberra, fieldwork was funded by the ACT Department of Health and Community Care, the NHMRC Psychiatric Epidemiology Research Centre at The Australian National University, and the Private Practice Trust Fund of The Canberra Hospital. In Melbourne, additional support for this research was provided by the Mental Health Branch, Department of Human Services, Victoria.

1.1 Survey planning and management

To ensure coherence of the objectives of the three arms of the study and highest possible methodological standards, a Technical Advisory Committee (see p. iv) was established to oversee the design and implementation of each study. A Low Prevalence Disorders Study Group of investigators (see p. iv) was responsible for the general design and methodology of this project, the coordination of field work, and data processing and analysis.

This report presents an overview of the methodology and findings of the study on low-prevalence disorders. The term *low-prevalence disorders* refers to the subset of mental illnesses known as *psychotic* disorders which comprises illnesses such as schizophrenia, schizoaffective disorder, delusional disorders, bipolar affective disorder and major depression with psychotic features, and acute or transient psychotic disorders. These disorders are characterised by prominent perceptual abnormalities (hallucinations), false beliefs (delusions), disorders of thought and speech (incoherence), persistent or episodic loss of insight and varying degrees of disorganised behaviour. So-called negative symptoms, including reduced initiative, motivation and interests, withdrawal from social contacts, and a flattening of emotional response, may be prominent features in schizophrenia. Although the population prevalence is low (1-2 per cent of all adults) in comparison with disorders such as anxiety and depression, the psychotic disorders are a major public health problem since they

- tend to run a long-term, sometimes lifelong, continuous or recurrent course;
- are associated with a disproportionate amount of severe disability and social dysfunction;
- account for a high proportion of the total resources allocated to mental health for services, including treatment and rehabilitation.

The subjective distress and diminished quality of life experienced by the sufferers, the impact of the illness on other family members and the community, and the stigma still attached to the image of 'madness' are important aspects of the high personal and social cost of the psychotic disorders.

According to World Health Organization and World Bank estimates², no less than 25 per cent of the total 'burden of disease' in the established market economies is at present attributable to neuropsychiatric conditions. Measured as a proportion of the 'disability-adjusted life years' (DALYs) lost, schizophrenia, bipolar affective disorder and major depression together account for 10.8 per cent of the total, and inflict on the community losses that are comparable to those due to cancer (15 per cent) and higher than the losses due to ischaemic heart disease (9 per cent).

Recent advances in neuroscience, genetics and pharmacology, as well as the accumulated experience with various forms of behavioural management and psychosocial interventions, improve greatly the prospect for a better scientific understanding of the causes of psychotic disorders and their effective treatment. However, the lives of the majority of the people with these disorders are today only marginally affected by such advances in knowledge and treatment technologies. The reasons why knowledge does not translate easily into practical programs at the community level are complex. Many people with psychotic illnesses are disadvantaged in multiple ways. They may lack or have lost occupational and social skills, and often experience economic adversity and social isolation. Their opportunities to learn and consolidate coping and living skills are jeopardised by the discontinuities in their lives brought about by relapses or exacerbations of psychotic symptoms. Over and above the direct neurocognitive sequelae of the illness itself, such as impairments of concentration and memory, the sense of being in control of their own lives is profoundly compromised in many individuals with psychotic disorders. This contributes to a sense of despondency that may explain the high risk of self-harming and suicide associated with this group of mental disorders.

As the problems associated with psychotic illness in the community are complex, the service response to it must be of a matching complexity. Designing and planning better services for people affected by psychotic illness requires better information than is available at present, not only on the number affected, but also with respect to their symptoms, their experience with services, and the quality of their daily living. Although schizophrenia and, to a lesser extent, affective psychoses have been the subject of many epidemiological inquiries worldwide, simple extrapolation from such sources cannot meet the information requirements of the National Mental Health Strategy. Previous investigations have either focused on *total* psychiatric morbidity in representative population samples where very few individuals exhibit psychotic symptoms (with the inevitable result that little usable information on low-prevalence disorders is generated), or produced detailed data on relatively small samples of patients with psychotic disorders which may not be representative of all those with such disorders in that community.

The present study aimed to overcome such limitations by combining an epidemiological survey which produced estimates of the number of people with psychotic illnesses as a proportion of the adult population in predominantly urban areas in Australia with a clinical and psychosocial inquiry into their histories, symptoms, functioning in daily life, service utilisation, and perceived needs. It is the first study of its kind conducted in Australia and one of the few worldwide that have set such goals and utilised a similar design.

2 Specific aims

The objective of the study was to estimate the prevalence of psychotic disorders and to obtain both a current ‘cross-sectional’ and a retrospective, longitudinal evaluation of the symptoms, associated impairments and disabilities; to gather information on services received and needed; and to explore aspects of quality of life in a sample that would be broadly representative of the people with psychotic illnesses living in urban areas in Australia. More specifically, the study aimed to generate:

Estimates of prevalence

- Point prevalence: the number of persons with current symptoms of psychotic disorders per 1000 population at risk

Clinical profile

- Symptom profiles: present (including last 4 weeks); past year; and lifetime ever
- Age at onset and length of previous illness
- Pattern of course, based on the number and duration of psychotic episodes, frequency of relapses and remission of symptoms

Measures of impairments and disabilities

- Severity scores of impairments and disabilities by diagnostic group, age and sex
- Activities of daily living

Profile of socio-economic condition

- Unemployment among people with psychotic mental illness
- Housing and accommodation, including homelessness among people with psychotic mental illness
- Educational qualifications

Description of service utilisation, treatment and perceived need for services

- Proportion of the point prevalence sample currently in hospital or institutions
- Proportion of the sample utilising community, other outpatient care, or rehabilitation services
- Proportion of the sample receiving treatment from different categories of service providers: public mental health services, general practitioners and private psychiatrists
- Availability of carers and supportive social network
- Proportion of the sample receiving psychopharmacological treatment, by type of medication
- Subjective evaluation by people with psychotic illnesses of their satisfaction with existing services and the need for services not currently available

Measures of quality of life

- Personal safety and need for police or legal assistance
- Victim of violence
- Feelings of despondency
- Suicidal ideation and self-harming behaviour
- Impairment in daily life due to medication side effects
- Satisfaction with own independence
- Satisfaction with life as a whole

3 Research teams

The study was conducted over four sites in four states. It was co-ordinated from Perth by the Project Director, Professor Assen Jablensky, in collaboration with the Study Group. Central co-ordination ensured uniformity between sites in the methodology employed throughout the course of the study. At the same time, each site maintained a separate research team that was responsible for the day-to-day management of the study at that site. The structure and membership of the research teams are summarised in Table 3.1.

Table 3.1 Project teams: Study of low-prevalence disorders

	<i>Australian Capital Territory</i>	<i>Queensland</i>	<i>Victoria</i>	<i>Western Australia</i>
Team Leader	Dr Mandy Evans	A/Prof John McGrath	Prof Helen Herrman	Prof Assen Jablensky
Deputy Team Leader			Dr Oye Gureje Dr Carol Harvey	Dr David Castle
Statistical/Technical Adviser	Prof Scott Henderson Ms Ailsa Kortzen Dr Stephen Rosenman	Dr David Chant	Dr Ian Gordon Dr Tom Trauer	
Project Co-ordinator	Ms Jo Medway	Ms Susette Cardy	Ms Helen Evert	Ms Vera Morgan Ms Anna Waterreus
DIP Supervisor	Dr Mandy Evans	Mr Chris Young	Dr Oye Gureje	Ms Anna Waterreus
Database Manager	Ms Jo Medway	Mr Ben Chapple	Mr Tony Pinzone	Ms Vera Morgan
Interviewers	Ms Helen Stoeckel Mr David Kirk Mr David Keys Ms Johann Napier	Ms Susette Cardy Mr Chris Young Ms Dianne Briffa Mr Ben Chapple Ms Suzanne Drake Ms Madonna Hirning Mr Troy Winterflood	Ms Helen Evert Ms Rosemary Thomas Ms Monique Decortis Ms Naomi Harris Ms Maggie McIntosh Mr Andrew Green Dr Susan Roberts	Ms Anna Waterreus Ms Jenny Griffith Ms Frances Waru Ms Elizabeth Trainer Mr Colin Sansom Ms Michelle Lusty
Other Support		Dr Kay Thomas Mr Roman Scheurer Mr Mark Milling		

4 Design and methods

4.1 General description of study design

The study was designed as a two-phase survey of geographically defined catchment areas in the Australian Capital Territory, Queensland, Victoria, and Western Australia.

4.2 Persons in current contact with the 'mainstream' mental health services

In the first phase, all individuals making contact with mental health services and service providers within the catchment areas in the course of a census month were screened for past and current symptoms or signs suggestive of psychotic disorder. In the second phase, a random sample of screen-positive individuals were approached with a request for an interview. Those who gave their signed, informed consent were interviewed with the Diagnostic Interview for Psychosis (DIP). Those who refused to be interviewed or were unavailable were compared with the subjects actually interviewed on several demographic and, where feasible, diagnostic variables in order to assess whether the interviewed sample differed in any systematic way from the total group of screen-positive subjects. To control for cases of psychotic disorder who might have been misclassified at the screening phase, a sample of screen-negative subjects was also interviewed.

Since subjects making a contact with mainstream services, specifically inpatient and outpatient services, during any given month were likely to be a fraction of the total number of people with psychotic disorders in the community, supplementary strategies were used to estimate the size and characteristics of three particular groups:

4.3 Persons having general practitioners or private psychiatrists as sole service providers

General practitioners and private psychiatrists providing services to residents of the catchment areas were surveyed by mail to identify those who had patients with psychotic disorders for whose management they were solely responsible, and to elicit their co-operation. Those who met the criterion of a 'sole carer' and who agreed to participate were visited by research staff and patients meeting the screening criteria for psychosis in the census month were sampled from their lists. Such patients were approached with an invitation to a DIP interview as described above.

4.4 Persons of no fixed abode, in transit, or in other marginal accommodation

Homeless people, people in transit accommodation provided by welfare/charitable organisations, and people in other marginal accommodation who were not in contact with any of the services identified above were located by research staff in the census month at night shelters, hostels or other ‘safety net’ services in the community. Screen forms were filled in with the subject’s consent and a number of screen-positive subjects were interviewed.

4.5 Persons with previous service contacts but not in contact with services in the census month

In addition to the groups described above who were targeted and screened in the census month, a further group was identified, consisting of those individuals who had previously been in contact with mainstream inpatient and outpatient services but who were not in contact with those services during the census month. Lists of people who had been in treatment for psychotic illness within the past three years but who had no recorded contact with services during the census month were compiled from service registries or information systems. Samples drawn from such lists were approached in writing and by telephone, and subjects giving consent were interviewed.

4.6 Inclusion criteria

The scope of the study was defined so as to include people with psychotic disorders that could be classified according to the International Classification of Diseases, 10th revision (ICD-10)³ as: Schizophrenia (F20); Schizoaffective disorders (F25); Manic episode with psychotic symptoms (F30.2); Bipolar affective disorder with psychotic symptoms (F31.2, F31.5); Severe depressive episode with psychotic symptoms (F32.3); Recurrent depressive disorder with psychotic symptoms (F33.3); Persistent delusional disorder (F22); Acute or transient psychotic disorder (F23); or Other and Unspecified non-organic psychotic disorder (F28, F29).

It should be noted that the definition of a ‘case’ of psychotic disorder in this study refers to *lifetime* diagnosis, that is, to episodes of psychotic illness at any time of a given person’s life – past or present. Thus, screening during the census month examined for evidence of psychotic disorder at any time in the past, as well as symptoms present during the census month. Some individuals meeting the criteria for a lifetime diagnosis may not have ‘active’ symptoms of psychosis at the time of screening or at interview. Some are in a remission, or their psychotic symptoms may be under pharmacological control. Such individuals were included if they met the screening criteria for lifetime occurrence of a psychotic disorder.

4.7 Exclusion criteria

Individuals who experienced brief psychotic episodes secondary to psychoactive substance intoxication or a medical condition were excluded since these disorders are infrequent, tend to be of brief duration, and rarely evolve into a prolonged or disabling psychiatric illness. It was considered that attempts to ascertain such disorders were unlikely to contribute to the aims of the study and would not be cost-effective. Examples of disorders not covered by the study would be a transient psychotic episode following use of hallucinogenic drugs or a postoperative delirium on a surgical ward.

Other exclusion criteria were:

- age less than 18 years or age 65 years and above;
- temporary visitor status in Australia;
- presence of significant cognitive deficit (dementia);
- presence of moderate, severe, or profound intellectual handicap;
- presence of severe communication impairment (for example, post-stroke aphasia);
- unavailability for screening or interviewing due to residence in an institution such as a nursing home or prison;
- inability to communicate in English to a degree allowing a valid interview.

4.8 Comment on the inclusion/exclusion criteria

- (i) The cut-off at 18 years of age for inclusion into the study was dictated by the legal age of consent. As regards the upper age limit at 65 years, the consideration was that the inclusion of elderly people with psychotic symptoms was likely to confront the field investigators with ascertainment issues such as a diagnostic differentiation between a schizophrenic or affective illness and an organic brain disorder. Such issues could not be dealt with in a satisfactory way with the methods and instruments chosen for this study and would require a specially designed, future investigation.
- (ii) People of Aboriginal/Torres Straits Islander background using the services at the study sites in the catchment area were screened and included on common grounds but no special effort was made in this survey to screen the users of dedicated Aboriginal mental health or medical services. Similarly, people of non-English speaking background were included if they met the inclusion criteria and were using the services designated as entry points for screening and recruitment for interviewing. Therefore, the indigenous Australians and the persons of non-English speaking background who were included and assessed in this study may not be representative of their respective communities. Since their numbers within the study population were relatively small, they are not identified as subgroups in the presentation of the results. It is expected that the epidemiology of mental health problems among the indigenous Australian population will be surveyed in future studies.

5 Characteristics of the four study areas

Table 5.1 Summary of census catchment areas

	Area				
	Australian Capital Territory	Queensland	Victoria	Western Australia	National figures
Estimated Resident Population (ERP) aged 18-64 (a)	205 849	581 332	148 812	148 985	–
Females (%)	50.2%	50.3%	51.6%	49.1%	–
Area (square kilometres)	2 359	12 745	80	440	–
Population density (persons aged 18-64 per km ²)	87.3	45.6	1860.2	338.6	–
Other characteristics (b)					
Population aged 0-14 (%)	22.7	22.7	15.9	16.7	21.6
Population aged 65 years and over (%)	6.7	9.3	12.8	12.7	12.1
Indigenous (%)	1.0	1.6	0.2	1.5	2.0
Australian-born (%)	74.3	74.4	68.9	62.0	73.9
Never married (%)	27.2	24.5	33.6	31.0	30.6
Private, occupied dwellings by tenure type (b)					
Fully owned	29.5	36.2	40.0	33.2	40.4
Being purchased	34.5	29.8	19.6	23.3	26.7
Being rented	32.1	28.9	33.8	36.4	26.7
Other	3.9	5.1	6.6	7.1	6.3
TOTAL private, occupied dwellings	100.0	100.0	100.0	100.0	100.0
Persons by dwelling type (b)					
Separate house	84.5	88.3	60.4	72.7	82.2
Semi-detached, terrace, townhouse	9.3	4.0	16.9	14.0	6.2
Flat, unit, apartment	5.2	4.8	19.4	11.2	8.4
Other (caravan, tent, flat attached to shop etc.)	0.2	1.0	1.1	0.4	1.5
Not stated	0.8	1.9	2.2	1.6	1.7
TOTAL persons	100.0	100.0	100.0	100.0	100.0
Educational attainment (population aged 18-64) (c)					
No post-school qualification (%)	46.1	58.0	41.5	51.4	–
Higher education qualification (%)	29.2	14.8	38.3	21.2	–
Index of Relative Socio-Economic Disadvantage (d) (median and range)	1094 (977-1162)	999 (780-1118)	1125 (805-1162)	1002 (881-1093)	994 (602-1180)
Index of Education and Occupation (d) (median and range)	1124 (1025-1237)	962 (842-1195)	1180 (984-1126)	1054 (920-1150)	960 (731-1271)
Postcodes including at least one rural CD (e) (%)	24.0%	49.4%	0.0%	17.4%	68.5%

(a) Estimated Resident population (ERP) data for 30 June 1997 were extracted by the Australian Bureau of Statistics (ABS)

(b) Census data for the catchment areas were extracted from the Australian Bureau of Statistics Census 1996 database Cdata96 using catchment area postcodes. The whole of a postcode area was used in these statistics even if only part of the postcode was selected for surveying (affecting six postcodes only). For full details on catchment area postcodes, see Appendix 2. Corresponding national figures were taken from the Australian Bureau of Statistics publications *Census of Population and Housing: Selected Social and Housing Characteristics, Australia* cat. no. 2015.0, and *Housing, Australia in Profile: A Regional Analysis 1996* cat. no. 2032.0.

(c) Catchment area data on qualifications were extracted by Australian Bureau of Statistics from Census 1996 files using Statistical Local Areas to approximate the postcodes in the catchment areas. 'No post-school qualification' refers to no post-school basic vocational or higher qualification. 'Higher education qualification' refers to an undergraduate degree/diploma or higher, but not a basic vocational post-school qualification.

(d) Index data were extracted from the Australian Bureau of Statistics database SEIFA96 using catchment area postcodes to obtain postal area level indexes. Index scores are standardised at the ABS collection district (CD) level so that the mean across all CDs in Australia is 1000 with a standard deviation of 100. The higher the score for the Index of Relative Socio-Economic Disadvantage, the less disadvantaged the catchment area (indicating fewer families of low income, little training and unskilled occupations), and the higher the score for the Index of Education and Occupation, the higher the concentration of persons with higher educational qualifications and higher skilled occupations. See Australian Bureau of Statistics (1998) *1996 Census of Population and Housing: Socio-economic Indexes for Areas*, ABS cat. no. 2039.0.

(e) Rural collection districts (CDs) are defined as those which are not within urban centres with a population of 1000 or over. Because the data in this table are based on postcodes which may include many CDs, it is possible for one postcode to include both urban and rural CDs. See Australian Bureau of Statistics (1998) *1996 Census of Population and Housing: Socio-economic Indexes for Areas*, ABS cat. no. 2039.0.

The survey was conducted within four geographically defined catchment areas in four Australian States and Territories: the Australian Capital Territory, Queensland, Victoria and Western Australia. The selection of areas was guided by several considerations. First, areas were chosen so as to maximise the probability that their residents would be using mental health services within the catchment area during the census month. Thus regions with well established, community-based mental health services and general practitioner liaison were selected. Second, it was important that services within a selected area were motivated to participate in the study and had the expertise and resources to support the census month screening. Finally, selection was made so that project teams could cover the whole of the area within the resources available to the study. A profile of each of the four catchment areas is given in Table 5.1.

Australian Capital Territory

The census covered the whole of the Australian Capital Territory (2,359 square kilometres) bar one postcode area that straddled the Australian Capital Territory/New South Wales border, and included Canberra where 99.9% of the population of the Australian Capital Territory resides. Leakage from the Australian Capital Territory to services in New South Wales is minimal since services in New South Wales operate on a geographical basis and generally do not admit residents of the Australian Capital Territory.

Queensland

The census in Queensland included Ipswich, Logan City and part of the City of Brisbane. The Queensland catchment area was markedly larger than any other catchment area (12,745 square kilometres) and covered a diverse range of localities including part of the densely populated inner city, urban, peri-urban and rural districts as well as offshore island communities.

Victoria

The census in Victoria concentrated on some 80 square kilometres of inner eastern Melbourne, specifically the Cities of Yarra and Boroondara which represent two very different socio-economic strata. The City of Boroondara is a predominantly middle class residential area. On the other hand, the City of Yarra is a traditionally working class area although this is changing somewhat with the increased popularity of inner city living. It includes large public housing estates and a number of rooming/boarding houses.

Western Australia

The census in Western Australia was conducted in a geographically defined area of contiguous suburbs within greater metropolitan Perth and included the inner city area, several northern suburbs, and a large tract of south-eastern suburbs ranging from suburban (both older and newer developments) to semi-rural districts. The catchment area in Western Australia covered 440 square kilometres.

The postcodes within each catchment area are given in Appendix 2.

6 Screening for psychotic disorders

The purpose of any screening test or procedure in medicine is to help classify a population into a group of people who are likely to have the disease or other attribute of interest (potential ‘cases’) and a group of people in whom the disease or attribute is unlikely to be present (‘non-cases’). A screening procedure must be quick, easy to administer, acceptable to the people to be screened, and low-cost. Above all, it must be *sensitive*, that is, capable of identifying as a potential ‘case’ everybody who really has the disease or attribute, and *specific*, that is, capable of excluding as ‘non-cases’ all those individuals who really do not have the disease or attribute. The *validity* of a given screening test may also be described in terms of its (i) *positive predictive value* (PPV) or the percentage of individuals correctly identified as ‘true cases’ out of all individuals scoring as positive on the screening test, and (ii) *negative predictive value* (NPV) or the percentage of individuals correctly classified by the screen as ‘non-cases’ out of all individuals scoring as negative on the screening test. The values of the PPV and NPV are, however, dependent on the prevalence of cases in the population being screened.

While a number of validated screening questionnaires are available for non-psychotic mental disorders, there is no established, generally accepted screening instrument for psychotic disorders that meets all of the criteria outlined above. It was therefore decided to design a screening procedure specifically for this study using selected elements of existing instruments such as the psychosis screening questions of the Composite International Diagnostic Interview (CIDI)⁴ and the Psychosis Screening Questionnaire (PSQ)⁵ and combining these with items drawing on a key worker’s clinical judgement. The protocol thus developed, the Psychosis Screen (PS), consists of a section recording subject identification and basic demographic data, a six-item section inquiring about the occurrence of specific psychotic symptoms (current or at any time in the past), and a section in which the key worker administering the PS records a judgement whether psychotic symptoms may be present. The PS was designed for use primarily by service staff, such as nurses or other key workers. For patients who are well known to the service and/or the key worker, the screening items are scored as present or absent on the basis of all information available to the rater (including case notes). For patients who are new to the service, the key worker is required to conduct a brief interview (5 minutes) asking each of the PS items in a questionnaire format.

As part of the preparatory work for the study, several alternative versions of the PS were pilot-tested in a series of 116 in-patients and outpatients, of whom 42 had clinical diagnoses of psychotic disorders and 74 had diagnoses of non-psychotic disorders. The performance of each one of the final set of 6 screening items according to validity criteria are listed in Table 6.1.

Table 6.1 Psychosis screen: Sensitivity, specificity and positive predictive value of individual items

<i>Item</i>	<i>Sensitivity</i>	<i>Specificity</i>	<i>Positive Predictive Value*</i>
Special powers	0.19	0.97	0.82
Strange happenings	0.80	0.58	0.52
Thoughts controlled	0.50	0.85	0.66
People too interested in subject	0.55	0.81	0.62
Hallucinations	0.56	0.79	0.48
Told may have schizophrenia	0.52	0.97	0.89

* based on the pilot sample of 116 patients with prevalence 0.36

A score of 2 (that is, any two or more screening items rated as positive) was selected as the cut-off point for the decision to consider a given individual a potential 'case'. This cut-off point provided the optimal trade-off between sensitivity and specificity within the pilot sample, with sensitivity and specificity of 67% and 84% respectively and a PPV at 70% and a NPV at 80%. In instances where the key workers felt unsure whether to score 1 or 2, they were instructed to err on the positive side and include rather than exclude such 'borderline' cases.

7 Clinical interview: The Diagnostic Interview for Psychosis (DIP)

The Diagnostic Interview for Psychosis (DIP) was the main assessment tool used in the study. It is a composite semi-structured, standardised interview schedule consisting of three modules:

- Demography and social functioning
- Diagnostic module (OPCRIT-SCAN)
- Service utilisation.

The structure and format of the DIP were developed specifically for this study. However, the DIP incorporates elements of internationally established instruments and is, therefore, capable of generating diagnostic data that are comparable with those produced by researchers in other parts of the world. Thus, the demography and social functioning module includes selected items from the World Health Organization Disability Assessment Schedule (WHO/DAS)⁶. The diagnostic module is designed around the Operational Criteria for Psychosis (OPCRIT)⁷, a 90-item checklist linked to a computer diagnostic algorithm which has been widely used internationally. While the original OPCRIT does not specify a procedure for eliciting the information necessary for rating the diagnostic items, the DIP module includes a structured clinical interview with questions derived and adapted from another international instrument, the World Health Organization Schedules for Clinical Assessment in Neuropsychiatry (SCAN)⁸. The content of the service utilisation module, on the other hand, reflects the structure and mode of operation of the mental health and social services in Australia.

The DIP is not a questionnaire simply recording the respondent's 'yes' or 'no' answers but a guide to a structured interview which requires clinical judgement for the rating of many of its items. For example, a decision about the presence or absence of a symptom is made on the basis of all information available and presupposes skills and experience acquired in work with people with mental health problems. The interview is flexible and, after asking a 'main' or mandatory question about an item, the interviewer can select from the suggested optional probes those most appropriate to the particular respondent. The order of the items can be varied if necessary, and in the course of the examination the interviewer may return to items asked earlier, if he/she is not satisfied that a rating is valid. The ratings are rule-based, in the sense that most of the items have a definition given either as a glossary note or embedded into the instructions to the interviewer accompanying each rating scale.

The DIP was designed for use by a variety of mental health workers, including psychiatrists, clinical psychologists and nurses. Since the majority of the interviews in this study were to be conducted by research assistants with a background in mental health nursing, special training procedures were designed and implemented to ensure quality standards and reliability of the assessments. In addition to training within each one of the four participating centres, two inter-centre workshops were conducted in which 14 interviewers rated jointly pre-recorded videotapes of DIP interviews and calibrated each other's ratings against the glossary criteria and the clinical judgement of an expert panel of psychiatrists on the same cases.

The reliability of a structured clinical interview is usually evaluated as the probability that two (or more) raters observing and independently rating the same interview will agree in their ratings. A commonly used statistic quantifying the degree of agreement (above the agreement that may be due to chance) is the *kappa* coefficient which assumes values in the range between 0 and 1. A kappa value of 0.50 and above is usually accepted as indicating a satisfactory level of agreement. Table 7.1 presents results from training sessions conducted before the survey in which 13 cases were rated jointly by a pair of interviewers and one case which was rated simultaneously by 13 interviewers. While the results indicated a generally adequate agreement, there were certain items with lower kappa values that necessitated additional training prior to the start of data collection.

Table 7.1 Diagnostic interview for psychosis: Inter-rater reliability

Agreement on OPCRIT diagnosis	Kappa (weighted) = 0.60 (p<0.01)	
Agreement on 89 OPCRIT/SCAN items	Kappa ranges:	
	> 0.60	19 items
	> 0.50	54 items
	< 0.50	16 items
	Pairwise agreement rate (PAR) ranges:	
	0.85 - 1.00	57 items
	< 0.85	33 items

8 Census of psychotic disorders in the four areas

The census of individuals with psychosis was conducted at each of the four areas over a period of 30 consecutive days between June and September 1997. Table 8.1 summarises the essential information describing the census by area. Data are presented on the type and number of services and agencies within the catchment area that were targeted for screening, the number of individuals screened (including the percentage of women screened, the percentage of positive screens, and the percentage of screens completed by a key worker rather than by self-report). The table also details the number of screen-positive individuals who met the inclusion/exclusion criteria and were sampled for interview, the number of persons interviewed and the number that could not be interviewed for various reasons including refusal, being too unwell to be interviewed, or failure of the project team to locate the person.

Table 8.1 Summary of census by area

	Area				Total
	Australian Capital Territory	Queensland	Victoria	Western Australia	
Census dates (a)	5 Aug – 3 Sep 97	1 Jun – 30 Jun 97	21 Jul – 19 Aug 97	4 Aug – 3 Sep 97	
Services, agencies involved in census (N)					
Inpatient units (public, private)	2	5	4	3	14
Outpatient units, day centres (public, private)	2	5	2	4	13
Residential care units	2	–	1	–	3
Community clinics	4	11	2	3	20
General practitioners (b)	12/294	41/1078	25/601	10/242	88/2215
Private psychiatrists (b)	13/17	5/41	14/340	20/67	52/465
Other screening agencies participating (N)					
Refuges	0	0	4	2	6
Drop-in centres	0	3	6	6	15
Marginal accommodation including units, flats (c)	3	50	30	5	88
Church and other welfare agencies	0	8	4	2	14
Other (d)	0	3	0	10	13
Census month screened population					
Total N screened, aged 18-64	1146	2180	1110	1274	5710
Females (%)	51.9%	41.0%	34.9%	44.8%	42.9%
Screen-positive (%)	62.9%	69.4%	64.0%	67.3%	66.5%
Screens completed by key worker (%)	94.6%	84.8%	67.5%	84.1%	83.4%
Census month sample (screen-positive)					
Total N interviewed	149	283	310	238	980
Total N identified as eligible for interview	293	618	627	464	2002
Total N eligible but lost to interview	144	335	317	226	1022
<i>Patient refusal</i>	80	144	133	123	480
<i>Key worker refusal (e)</i>	7	110	41	36	194
<i>Patient moved away, unable to contact</i>	51	79	78	63	271
<i>Other (not approached, died, too unwell etc.)</i>	6	2	65	4	77
Census month sample (screen-negative)					
Total N interviewed	16	15	14	21	66
Total N identified as eligible for interview and contact attempted	50	28	23	42	143
Total N eligible but lost to interview (f)	34	13	9	21	77
Sample whose last contact with mainstream services was in the 11 months prior to census month					
Total N interviewed	24	20	31	23	98
Total N identified as eligible for interview and contact attempted	157	51	98	123	429
Total N eligible but lost to interview	133	31	67	100	331
<i>Patient refusal</i>	12	8	18	20	58
<i>Key worker refusal, too unwell</i>	5	6	4	7	22
<i>No contact achieved</i>	116	17	45	73	251
Sample whose last contact with mainstream services was 12-36 months prior to census month					
Total N interviewed	11	4	27	6	48
Total N identified as eligible for interview and contact attempted	164	43	104	61	372
Total N eligible but lost to interview (f)	153	39	77	55	324

(a) While the census in Western Australia covered 31 days, only a couple of additional cases were identified on the 31st day of the census.

(b) Number of general practitioners/private psychiatrists who actually participated in the survey out of the number approached for participation. Actual participation was determined by a number of factors including the number of psychotic patients under the sole care of a clinician as well as the clinician's willingness to participate.

(c) A block of units etc. is counted as 1 in this table.

(d) 'Other' includes Aboriginal services, self-help groups, employment services, counselling services etc.

(e) Where practicable, case managers assessed if a patient was well enough to be interviewed.

(f) The category 'lost to interview' includes refusals, those who were too unwell to be interviewed and those who could not be contacted.

9 Estimates of the prevalence of psychotic disorders

The prevalence rate is the total number of individuals who have the disorder at a particular time (or during a particular period) divided by the population at risk of having the disorder at that given time. Epidemiological studies estimating the prevalence of schizophrenia and related psychotic disorders have been conducted since the early decades of this century. The results of studies carried out at different times and in different parts of the world (Table 9.1) suggest that, notwithstanding cultural and biological differences between populations, and the different methods used to ascertain morbidity, the prevalence of schizophrenia is remarkably similar around the world (in the range between 2 and 5 per 1000 according to the majority of studies) and stable over time. A World Health Organization study⁹ on the *incidence* of schizophrenia (the number of individuals developing the disorder for the first time during a particular period) in which standardised methods of case detection, interviewing and diagnosis were applied simultaneously in 10 countries, found little variation in the incidence rates of schizophrenia across the different populations and cultures (Table 9.2). The estimated lifetime risk for schizophrenia (the probability that an individual will develop the disease within a lifetime) derived from the data of the WHO study was in the range of 0.50 to 1.72 per cent.

There are, however, few studies in the world literature reporting on the prevalence of psychotic disorders as a group, cutting across diagnostic boundaries. Thus, while schizophrenia, delusional disorders and acute transient psychoses are, by definition, psychotic disorders, the large diagnostic group of mood (affective) disorders includes conditions manifesting psychotic symptoms (for example, mania or major depression with psychotic features) as well as conditions without such symptoms. Since psychotic disturbances, regardless of their causes and the context in which they occur (affective or schizophrenic disorder) have important treatment, management and prognostic implications, and are particularly distressing to the patients who experience them, an advantage of the present study was the opportunity to generate estimates of their prevalence.

Table 9.1. Selected prevalence studies of schizophrenia

<i>Author</i>	<i>Country</i>	<i>Population</i>	<i>Method</i>	<i>Prevalence per 1000</i>
Brugger (1931) ¹⁰	Germany	Area in Thuringia (n=37 561); age 10+	Census	2.4 (point)
Strömngren (1938) ¹¹ ; Bøjholm and Strömngren (1989) ¹²	Denmark	Island population (n=50 000)	Repeat census	3.9 → 3.3 (lifetime)
Lemkau et al. (1943) ¹³	USA	Household sample	Census	2.9 (point)
Sjögren (1948) ¹⁴	Sweden	Island population (n=25 000)	Census	4.6 (lifetime)
Böök (1953) ¹⁵ ; Böök et al. (1978) ¹⁶	Sweden	Genetic isolate (n=9000); age 15-50	Census	9.5 → 17.0 (lifetime)
Essen-Möller et al. (1956) ¹⁷ ; Hagnell (1966) ¹⁸	Sweden	Community in southern Sweden	Repeat census	6.7 → 4.5 (lifetime)
Rin and Lin (1962) ¹⁹ ; Lin et al. (1989) ²⁰	Taiwan	Population sample	Repeat census	2.1 → 1.4 (point)
Bash and Bash-Liechti (1969) ²¹	Iran	Rural area (n=11 585)	Census	2.1 (point)
Crocetti et al. (1971) ²²	Croatia	Sample of 9201 households	Census	5.9 (lifetime)
Dube and Kumar (1972) ²³	India	4 areas in Agra (n=29 468)	Census	2.6 (point)
Temkov et al. (1975) ²⁴	Bulgaria	Urban area (n=140 000)	Census	2.8 (point)
Rotstein (1977) ²⁵	Russia	Population sample (n=35 590)	Census	3.8 (point)
Keith et al. (1991) ²⁶	USA	Aggregated data across 5 ECA sites	Sample survey	7.0 (point) 15.0 (lifetime)
Jeffreys et al. (1997) ²⁷	UK	London health district (n=112 127)	Census; interviews of a sample (n=172)	5.1 (point)

Table 9.2. Selected incidence studies of schizophrenia

<i>Author</i>	<i>Country</i>	<i>Population</i>	<i>Method</i>	<i>Rate per 1000 /per year</i>
Ödegaard (1946) ²⁸	Norway	Total population	First admissions 1926-35 (n=14 231)	0.24
Walsh (1969) ²⁹	Ireland	City of Dublin (n=720 000)	First admissions	0.57 (male) 0.46 (female)
Häfner and Reimann (1970) ³⁰	Germany	City of Mannheim (n=330 000)	Case register	0.54
Murphy and Raman (1972) ³¹	Mauritius	Total population (n=257 000)	First admissions	0.24 (Africans) 0.14 (Indian Hindus) 0.09 (Indian Moslems)
Lieberman (1974) ³²	Russia	Moscow district (n=248 000)	Follow-back of prevalent cases	0.20 (male) 0.19 (female)
Helgason (1977) ³³	Iceland	Total population	First admissions 1966-67 (n=2388)	0.27
Lin et al. (1989) ²⁰	Taiwan	3 communities (n=39 024)	Household survey	0.17
Castle et al. (1991) ³⁴	UK	London (Camberwell)	Case register	0.25 (ICD) 0.17 (RDC) 0.08 (DSM-III)
Jablensky et al. (1992) ⁹	Denmark, India, Ireland, Japan, Russia, UK, USA	Eight catchment areas (Aarhus, Chandigarh urban and rural, Dublin, Honolulu, Moscow, Nagasaki, Nottingham)	First-contact case finding	0.18 (Aarhus) 0.35 (Chandigarh – urban) 0.26 (Chandigarh – rural) 0.22 (Dublin) 0.16 (Honolulu) 0.28 (Moscow) 0.21 (Nagasaki) 0.24 (Nottingham)
Nicole et al. (1992) ³⁵	Canada	Area in Quebec (n=338 300)	First admissions	0.31 (ICD) 0.09 (DSM-III)
Rajkumar et al. (1993) ³⁶	India	Area in Madras (n=43 097)	Door-to-door survey and key informants	0.41
Hickling and Rodgers-Johnson (1995) ³⁷	Jamaica	Total population (n=2.46 mln)	First contacts	0.24 ('broad') 0.21 ('restrictive')
McNaught et al. (1997) ³⁸	UK	London health district (n=112 127)	2 censuses, 5 years apart	0.21 (DSM-III-R)
Brewin et al. (1997) ³⁹	UK	Nottingham	2 cohorts of first contacts (1978-80 and 1992-94)	0.25 → 0.29 (all psychoses) 0.14 → 0.09 (ICD-10 schizophrenia)

9.1 Methods of estimation of prevalence rates

Details of the calculation of the prevalence rates are given in Appendix 1. All rates refer to any ICD-10 diagnosis of schizophrenia, schizoaffective disorder, delusional and other psychoses, bipolar disorder, mania or severe depression with psychosis.

Four sets of estimates were generated:

- One-month prevalence rates of persons with ICD-10 psychotic disorders making contact with mainstream inpatient and outpatient services, by age and sex.
- One-month prevalence rates of persons with ICD-10 psychotic disorders making contact only with services provided by private psychiatrists and general practitioners, by age and sex.
- 12-month prevalence rates of persons with ICD-10 psychotic disorders making contact with mainstream inpatient and outpatient services, by sex.
- Prevalence rates of persons with ICD-10 psychotic disorders who are marginalised or homeless and not identified in other service settings, by sex.

It should be noted that rates refer to the number of *individuals* seen and not to the number of occasions of service. There is no separation of incident (new) cases from prevalent cases, and the study did not attempt to derive incidence estimates from the prevalence estimates.

General assumptions governing the calculation of the rates were that all patients making contact with mainstream services during the census month were screened; that sampling for the DIP interview was random within each of the strata formed by the screen positives and screen negatives for all services covered; and that the ICD-10 diagnosis produced by the DIP was the 'gold standard'. Specific assumptions governing the estimates for private services, the 12-month rates and the rates of patients unknown to any mental health service are outlined in the Appendix 1.

The age and sex distribution of the estimated resident population of each catchment area are given in Table 9.3.

Table 9.3 Estimated Resident Population (ERP): Age and sex distribution of catchment areas for 30 June 1997 (Number)

Age group	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Males				
18-24	19 991	52 575	13 273	14 793
25-34	25712	72141	20614	20562
35-44	24249	70050	15327	17345
45-54	21411	59594	14252	14210
55-64	11078	34787	8520	8994
18-64	102441	289147	71986	75904
Females				
18-24	19411	51406	14679	15170
25-34	26153	74315	21143	19015
35-44	25478	73635	17229	16233
45-54	21645	59061	14950	13297
55-64	10721	33768	8825	9366
18-64	103408	292185	76826	73081
Persons				
18-64	205 849	581 332	148 812	148 985

9.2 Summary of results on prevalence of psychosis

Across all four sites, it is estimated that between 3 and 5 per 1000 adults (3–6 males, 2–4 females) have a psychotic disorder for which they seek care in a mainstream service during a 30-day period. A further 1 to 2 per 1000 adults (1–2 males, 1–3 females) with psychotic disorders seek care with private practitioners during the same time period. Between 0.5 and 1.2 adults per 1000 (0.7–1.4 males, 0.4–1.1 females) have attended a mainstream service in the previous 11 months but not any service in the census month, leading to 12-month prevalence rates of between 3 and 6 per 1000 adults (4–7 males, 3–5 females) treated in mainstream services. Across all sites except Victoria, the number of adults estimated to have a psychotic illness but to be marginalised or homeless is below 0.3 per 1000 (0.4 for males, 0.2 for females); in Victoria, the rate is as high as 1.3 per 1000 adults (2.0 for males, 0.6 for females).

It is possible to estimate the treated prevalence across the four sites combined by using a weighted mean, although the resultant estimate should be treated with caution. This estimate of the overall treated prevalence for contact with any service within a one-month period is 4.7 per thousand (5.2 for males, 4.1 for females).

9.3 One-month prevalence rates of psychotic disorders

Figures 9.1 and 9.2 and Table 9.4 show the estimated one-month prevalence rates per 1000 population of patients using mainstream services by sex and 10-year age group. For men, the pattern of prevalence is similar across the sites although the level varies from 3.12 in the Australian Capital Territory to 5.94 in Western Australia. The highest rates are seen in the age groups 25 to 44. For women, the pattern by age is also similar across the sites, but differs from that seen in males. Although the overall rates are lower in females, they tend to increase with age so that the rates in the oldest age groups are higher in females than in males.

Table 9.4 Estimated monthly treated prevalence of ICD-10 psychotic disorders in mainstream services (Rate per 1000 of ERP)

Age group	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Males				
18-24	3.00	2.97	3.79	4.98
25-34	3.97	4.27	4.49	7.06
35-44	4.12	3.43	6.24	7.27
45-54	1.82	3.19	3.93	5.24
55-64	1.72	2.79	3.79	3.12
18-64	3.12	3.43	4.56	5.94
Females				
18-24	1.93	1.16	1.29	2.57
25-34	2.05	2.04	2.65	4.15
35-44	3.55	2.37	3.78	4.75
45-54	2.53	2.53	4.00	5.44
55-64	2.63	3.20	3.30	4.23
18-64	2.63	2.20	3.00	4.23
Persons				
18-64	2.88	2.81	3.75	5.10

Figure 9.1 Estimated monthly treated prevalence of ICD-10 psychotic disorders in mainstream services per 1000 ERP (males)

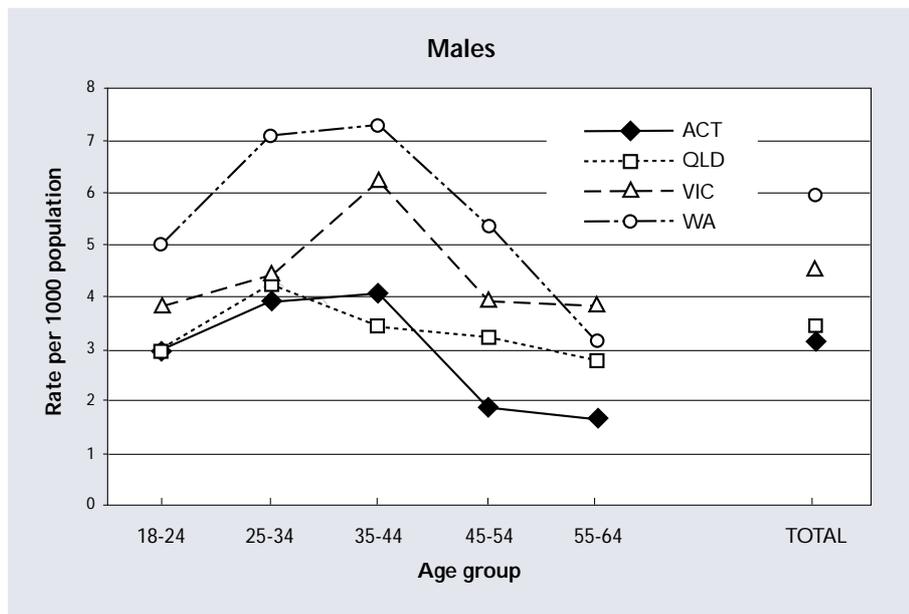
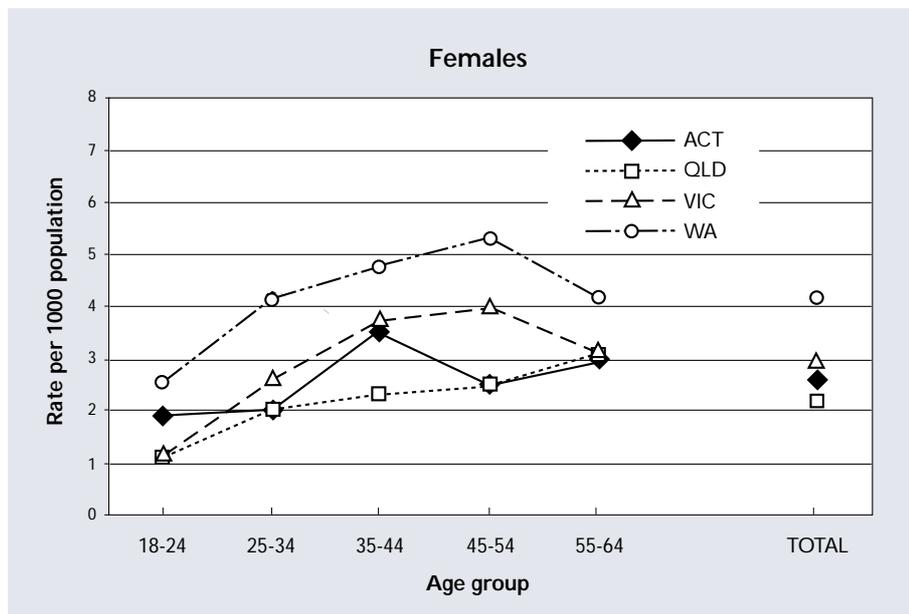


Figure 9.2 Estimated monthly treated prevalence of ICD-10 psychotic disorders in mainstream services per 1000 ERP (females)



Patients seen in the private sector numbered about half those seen in mainstream services. The pattern of prevalence was somewhat different (Table 9.5) with the rates for males dropping less rapidly with age, and the rates for females being higher than for males except in Queensland. These rates represent conservative estimates because of assumptions made about non-response on the part of practitioners (see Appendix 1).

Table 9.5 Estimated monthly treated prevalence of ICD-10 psychotic disorders in private treatment services (general practitioners and private psychiatrists) (Rate per 1000 of ERP)

Age group	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Males				
18-24	0.26	1.01	0.30	0.33
25-34	1.12	1.54	1.62	1.15
35-44	1.52	1.81	2.43	0.94
45-54	1.07	2.31	1.51	3.25
55-64	0.94	0.69	1.84	2.09
18-64	1.02	1.56	1.47	1.45
Females				
18-24	0.57	0.47	0.47	0.48
25-34	0.49	0.95	2.86	0.64
35-44	1.66	1.31	3.43	2.34
45-54	1.10	1.69	4.72	4.55
55-64	1.89	1.06	2.02	3.75
18-64	1.06	1.12	2.80	2.10
Persons				
18-64	1.04	1.34	1.75	1.77

When the two estimates are combined to provide one-month prevalence rates for persons with ICD-10 psychotic disorders and making contact with mental health services (Table 9.6), the rates for males are still higher than for females for ages below 45.

Table 9.6 Estimated monthly treated prevalence of ICD-10 psychotic disorders in mainstream and private treatment services combined (Rate per 1000 of ERP)

Age group	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Males				
18-24	3.26	3.98	4.09	5.31
25-34	5.09	5.81	6.11	8.22
35-44	5.64	5.24	8.67	8.22
45-54	2.89	5.50	5.44	8.50
55-64	2.66	3.48	5.63	5.21
18-64	4.14	4.99	6.03	7.39
Females				
18-24	2.50	1.63	1.70	3.05
25-34	2.36	2.99	5.51	4.80
35-44	5.31	3.68	7.21	7.09
45-54	3.67	4.22	8.72	9.99
55-64	4.90	4.26	5.32	7.98
18-64	3.68	3.32	5.80	6.33
Persons				
18-64	3.91	4.15	5.91	6.87

9.4 Twelve-month prevalence rates

An indication of the difference between one month and 12-month prevalence can be obtained for cases treated by mainstream services. Since a different sampling frame and screening process was used for patients using services in the 11 months preceding census month, these comparisons must be treated with caution. Table 9.7 shows 12-month rates by sex, which are 13 to 30 percent higher than the corresponding one-month rates. No comparative data are available for 12-month prevalence of patients using private mental health services only.

Table 9.7 Estimated 12 month treated prevalence rate of ICD-10 psychoses in mainstream services (Rate per 1000 of ERP)

Prevalence period	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Males				
One month rate	3.12	3.43	4.56	5.94
Rate previous 11 months	1.37	0.65	0.97	0.80
Total 12 month rate	4.49	4.08	5.53	6.74
Females				
One month rate	2.63	2.20	3.00	4.23
Rate previous 11 months	1.08	0.35	0.52	0.55
Total 12 month rate	3.71	2.55	3.52	4.78
Persons				
One month rate	2.88	2.81	3.75	5.10
Rate previous 11 months	1.22	0.50	0.74	0.68
Total 12 month rate	4.10	3.31	4.49	5.78

9.5 Rate of psychotic disorders in marginalised or homeless populations not identified in other service settings

Table 9.8 shows the rates of psychotic disorders identified in marginal accommodation settings in the four sites. In the Victoria catchment area, which is known to contain a concentration of homeless people and people living in marginal accommodation, the research team undertook a special effort to ascertain the cases among this population. The data suggest that the bias resulting from regarding the treated prevalence as an indicator of the underlying prevalence in the community may be small.

Table 9.8 Estimated point prevalence of ICD-10 psychotic disorders in marginalised or homeless sample and not identified in other service settings (Rate per 1000 of ERP)

Age group	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Males				
18-64	0.09	0.37	2.04	0.40
Females				
18-64	0.01	0.16	0.59	0.10
Persons				
18-64	0.05	0.25	1.29	0.25

10 Characteristics of the interviewed sample

The patient status of the interviewed sample at the point of recruitment into the study is shown for the four study areas in Table 10.1. Inpatients accounted for 26.7% of the sample while 61.0% were receiving outpatient or other non-residential care. The majority (687 participants or 70.1%) were recruited through the mainstream (public) mental health services. Another 173 participants (17.7%) were recruited through their general practitioners or private psychiatrists. Lastly, 120 persons (12.2%), many of these living in marginal accommodation or with no fixed address in the study areas, were recruited outside of treatment services through crisis accommodation or community aid services.

A hierarchy was used to allocate unique recruitment status to participants who had been identified through more than one type of service during the census month. Inpatient services were at the top of the hierarchy, followed by outpatient services, contacts with private psychiatrists and contacts with general practitioners. Participants were accorded the status that was highest in the hierarchy. Subjects identified outside of mainstream treatment facilities (for example, in marginal accommodation) who had not been identified through the other services were classified as ‘marginal, homeless’.

Table 10.1 All persons: Status at recruitment by area (per cent)

<i>Status at recruitment</i>	<i>Area</i>				<i>Total</i>
	<i>Australian Capital Territory</i>	<i>Queensland</i>	<i>Victoria</i>	<i>Western Australia</i>	
Inpatient	25.5	36.4	14.5	31.9	26.7
Outpatient	51.7	24.0	52.3	49.6	43.4
Private psychiatrist patient	12.1	12.7	6.1	5.9	8.9
General practitioner patient	6.0	12.7	8.1	6.7	8.8
Marginal, homeless	4.7	14.1	19.0	5.9	12.2
Total	100.0	100.0	100.0	100.0	100.0
Total persons	149	283	310	238	980

11 Demographic profile of the interviewed sample

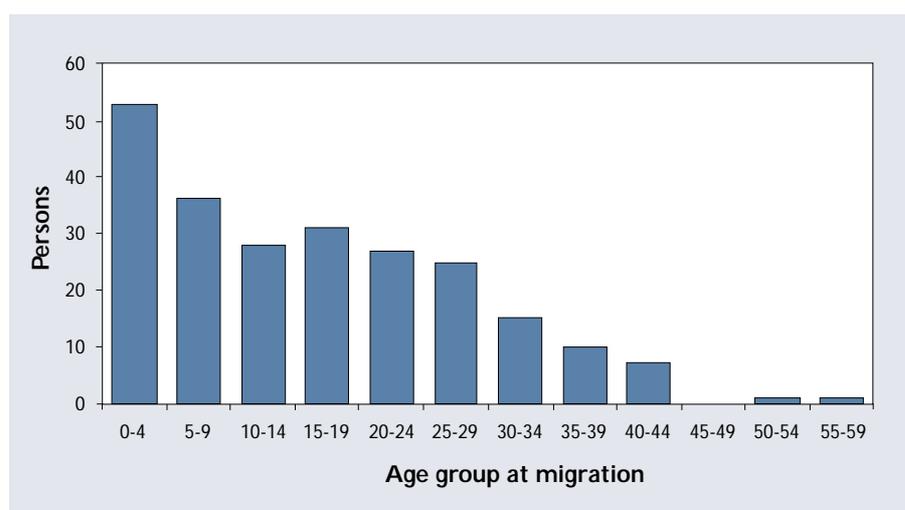
A total of 980 residents of the four areas (586 men and 394 women) gave informed consent to participate in the study and were successfully interviewed. A breakdown of participants by age group and sex is shown in Table 11.1.

Table 11.1 All persons: Age group by sex (per cent)

Age group (years)	Males	Females	Total
Under 25	13.1	9.6	11.7
25 – 34	29.2	21.1	25.9
35 – 44	28.2	26.9	27.7
45 – 54	19.1	28.4	22.9
55 and over	10.4	14.0	11.8
Total	100.0	100.0	100.0
Total persons	586	394	980

The great majority (75.9% of the sample) were Australia-born, with 3.7% of the total sample (4.8% of those born in Australia) of Aboriginal or Torres Strait Islander descent. The largest sub-group by country or region of birth among the 236 overseas-born participants came from UK or Ireland (8.9%) or the rest of Europe, including the former USSR (4.8%). In all, 133 participants (13.6%) indicated that they spoke a language other than English at home. The age at immigration for the overseas-born subset of the sample is plotted in Figure 11.1.

Figure 11.1 Persons born overseas: Age group at migration



The marital status of participants is shown in Table 11.2.

Table 11.2 All persons: Marital status by sex (per cent)

<i>Marital status</i>	<i>Males</i>	<i>Females</i>	<i>Total</i>
Single, never married	76.6	43.9	63.5
Married, de facto	10.1	24.6	15.9
Separated, divorced, widowed	13.3	31.5	20.6
Total	100.0	100.0	100.0
Total persons	586	394	980

A large proportion of the sample (58.1%) had left school at age 16 years or earlier. Table 11.3 presents the educational qualifications of participants and indicates that 47.8% of the sample had neither completed secondary schooling nor attained any further post-school qualification. This compares with a figure of 36.8% for the Australian population aged 15-64 and no longer at school.⁴⁰ A total of 114 participants (11.6%) had achieved a tertiary education diploma or degree (including 6 individuals who had completed a Masters or PhD degree). At the time of the interview, 147 participants (15.0%) were continuing their education full-time or part-time.

Table 11.3 All persons: Educational attainment by sex (per cent)

<i>Educational attainment</i>	<i>Males</i>	<i>Females</i>	<i>Total</i>
No school qualification	48.1	47.2	47.8
Secondary education	17.9	17.8	17.9
Trade or other certificate	22.0	17.0	20.0
Undergraduate, postgraduate award	9.4	15.0	11.6
Other	2.6	3.0	2.8
Total	100.0	100.0	100.0
Total persons	586	394	980

The type of accommodation that study participants were living in at the time of the survey is shown in Table 11.4. Other socio-economic characteristics of the sample are discussed in Section 14.

Table 11.4 All persons: Type of accommodation in past month (number, per cent)

<i>Accommodation type (a)</i>	<i>N</i>	<i>%</i>
Rented home (public, private)	308	31.4
Family home	146	14.9
Own home	142	14.5
Accommodation type other than rented, family or own home	438	44.7
<i>Breakdown of accommodation type other than rented, family or own home:</i>		
Institution (hospital, nursing home)	192	19.6
Hostel	133	13.6
Group home	28	2.9
Supported housing, rooming house, hotel/rented room, crisis shelter, homeless, no fixed address	111	11.3
<i>Breakdown of supported housing, rooming house, hotel/rented room, crisis shelter, homeless, no fixed address:</i>		
Rooming house, hotel/rented room, crisis shelter, homeless, no fixed address	86	8.8
Supported housing	25	2.6

(a) An individual may have used more than one type of accommodation in the month prior to interview

12 Diagnoses, course of illness and symptoms

12.1 Diagnostic classification

The diagnostic classification of mental health problems sorts the variable presentations of symptoms and behaviours into *disorders* on the basis of similarity of symptoms and signs, as well as on the basis of features that help distinguish between individual disorders. Diagnostic classification is clinically useful because it guides the search for causes and risk factors and assists both in identifying patterns of illness that have a relatively specific prognosis and response to treatment and in the choice of intervention.

Although the psychotic illnesses in the majority of the participants in this study had been diagnosed at the time of previous service contacts, each participant had a face-to-face semi-structured interview with a member of the research team using the DIP. The aim was twofold: to produce a uniform diagnostic classification of the illnesses these people had experienced, based on standard and internationally agreed diagnostic criteria; and to obtain information on past and present symptoms, and on their course and treatment response. This information served as input for the computerised diagnostic algorithm OPCRIT which generated a diagnostic classification of the cases according to several alternative classification systems. The diagnostic data in this report are presented in terms of the International Classification of Diseases, 10th Revision (ICD-10). In addition, a classification of the cases is presented according to the Diagnostic and Statistical Manual (DSM-III-R) of the American Psychiatric Association since this system is also widely used.

Both ICD-10 and DSM-III-R are criteria- and rule-based classifications, with the assignment of an individual's clinical presentation to a particular diagnostic category following explicit decision rules that stem from an agreed definition of the disorder. They also aim to minimise error due to missing information or subjective bias on the part of the diagnostician.

Table 12.1 presents the diagnostic breakdown of the interviewed sample of 980 individuals according to major ICD-10 and DSM-III-R categories. A more detailed classification specifying subtypes of the disorders is provided in the Appendix 3.

Table 12.1 All persons: Disorder by diagnostic classification system (per cent)

Disorder	Diagnostic classification system	
	ICD-10	DSM-III-R
Schizophrenia	52.0	50.6
Schizoaffective disorder	10.4	9.2
Bipolar disorder, mania	11.4	18.8
Depressive psychosis	8.1	10.8
Other psychosis	14.8	8.9
Did not meet criteria for psychosis	3.3	1.7
Total	100.0	100.0
Total persons	980	980

In terms of ICD-10, the majority of the individuals in the one-month census met the criteria for schizophrenia (52.0%) or schizoaffective disorder (10.4%). A further 19.5% were diagnosed as affective disorder (bipolar mania or depression) with psychotic features and 14.8% were assigned to the category of other non-organic psychosis. The remaining 3.3% did not meet ICD-10 criteria for one of the above diagnoses. The diagnostic distribution of the sample in terms of DSM-III-R is similar as regards schizophrenia and schizoaffective disorder. Within these two categories, the diagnostic concordance between ICD-10 and DSM-III-R (the proportion of cases with identical diagnosis according to the two systems) is 80.0%. As regards affective psychoses and other non-organic psychoses, there is a tendency for ICD-10 to allocate a number of cases classified as affective disorders by DSM-III-R to the category of ‘other’ psychotic disorders (including acute and transient psychoses). This explains the lower diagnostic concordance between the two classifications for affective psychoses (57.1%).

12.2 Age at onset

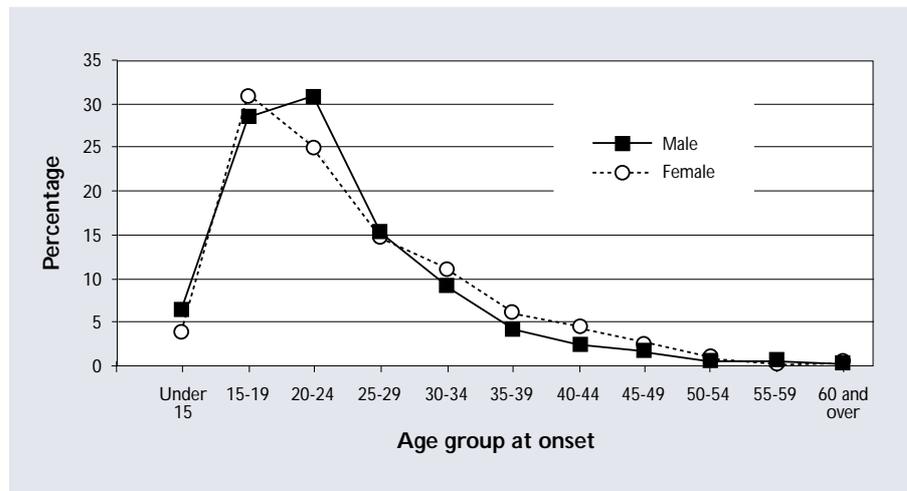
The psychotic illnesses in this study tend to have their onset in the early to mid-twenties, with the exception of depressive psychoses where the mean age at onset is in the late twenties (Table 12.2).

Females tend to have a slightly later onset than males (Figure 12.1) but the difference is not statistically significant. There are no statistically significant differences with regard to mean age at onset between the four sites or between the different sources of recruitment.

Table 12.2 All persons: Age at onset of psychiatric illness

	<i>Age at onset of psychiatric illness (years)</i>	
	<i>mean</i>	<i>standard deviation</i>
Sex		
Males	23.8	8.7
Females	24.8	9.1
Broad ICD-10 diagnosis		
Schizophrenia	23.4	7.8
Schizoaffective	22.6	6.1
Bipolar mania	25.7	9.8
Depressive psychosis	28.0	11.5
Other psychosis	24.0	9.8
Area		
Australian Capital Territory	23.9	9.1
Queensland	22.8	8.8
Victoria	24.8	8.3
Western Australia	25.2	9.3
Source of recruitment		
Mainstream (inpatient, outpatient) services	23.9	8.6
General practitioner, private psychiatrist	25.0	9.3
Outside of standard treatment services	24.7	9.6
Contact with services prior to census month but not in census month	26.6	9.1
Total	24.2	8.8

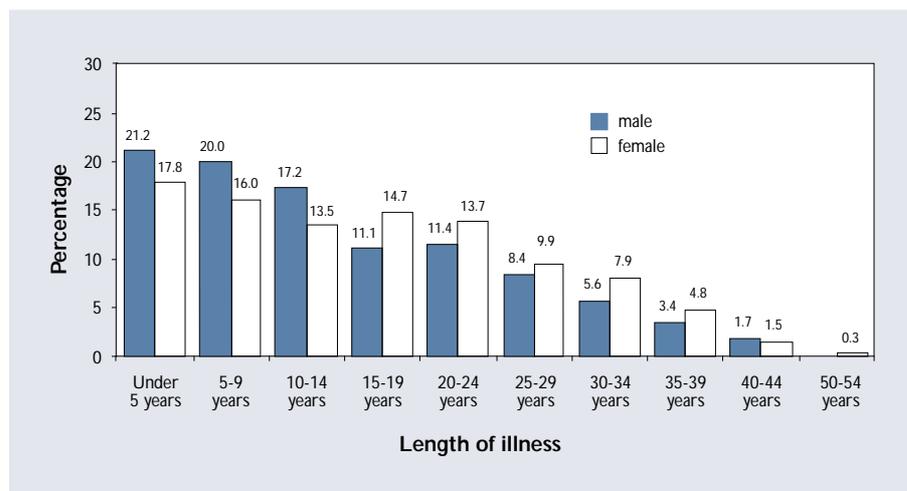
Figure 12.1 All persons: Age group at onset of disorder by sex



12.3 Length of psychiatric illness and pattern of course

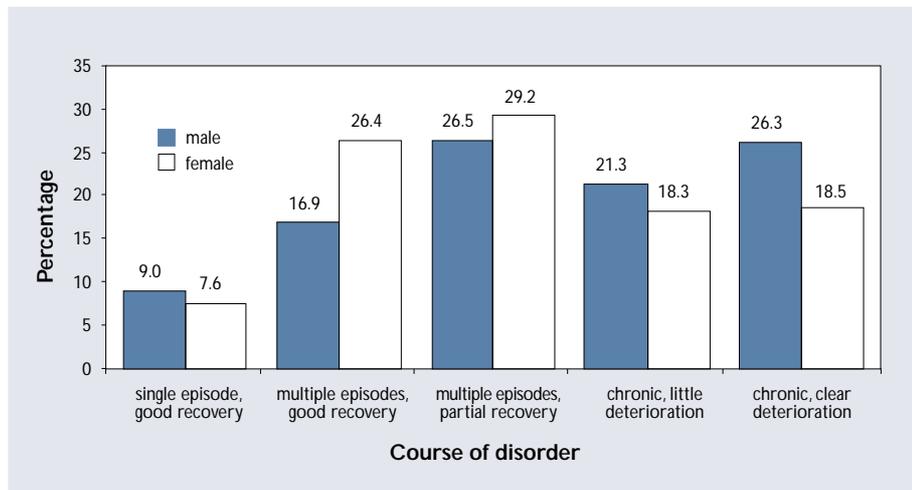
The mean length of illness prior to interview was 15.1 years. The majority of participants had a history of illness spanning 10 years or more, and only 19.8% had had a first onset of psychotic illness within the previous four years. Figure 12.2 illustrates the different pattern of length of illness for males and females.

Figure 12.2 All persons: Length of psychiatric illness by sex



The frequency of the different patterns of course of the psychotic disorders over time is shown in Figure 12.3.

Figure 12.3 All persons: Course of disorder by sex



Although a sizeable proportion (20.7%) had periods of recovery and a minority (8.5%) had experienced a single episode of illness, in the majority of cases (70.8%) the psychotic illness was either chronic or recurrent with only partial recovery between the episodes. Deterioration of functioning, compared with the peak level achieved prior to illness onset, was found to be present in 79.5%. A greater percentage of men (26.3%) than women (18.5%) had chronic illness with severe deterioration of functioning.

12.4 Symptoms

The examination of the clinical characteristics of the sample at the level of symptoms experienced at different time periods provides an insight into the subjective worlds of people affected by psychotic illness. Table 12.3 (top panel) lists the numbers of persons and percentages of the total sample experiencing 10 specified symptoms (or symptom clusters) at the time of the interview or during the preceding 4 weeks (present state) as well as at any time in their lives (lifetime, including both past and present).

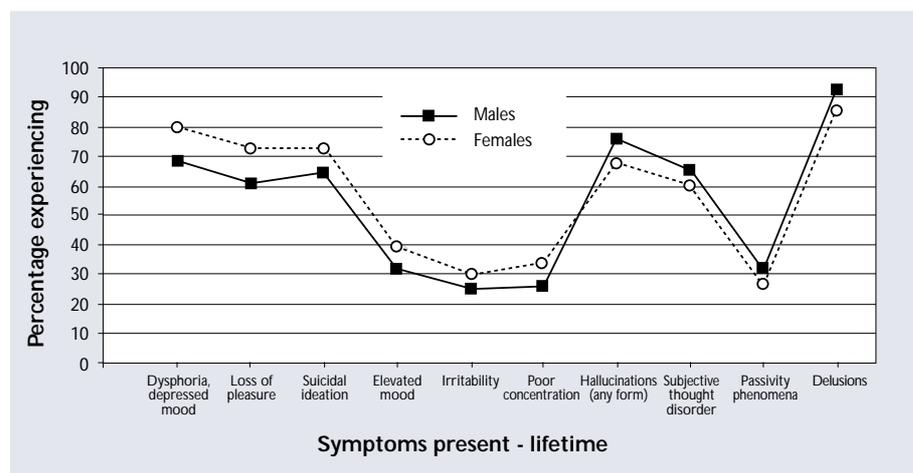
Table 12.3 All persons: Frequency of specific symptoms

Symptom	Present state (a)		Lifetime	
	N	%	N	%
Dysphoria/depressed mood	229	23.4	716	73.1
Loss of pleasure	207	21.1	641	65.4
Suicidal ideation	178	18.2	663	67.7
Elevated mood	54	5.5	341	34.8
Irritability	56	5.7	265	27.0
Poor concentration	63	6.4	285	29.1
Hallucinations (any form)	354	36.1	715	73.0
Subjective thought disorder	335	34.2	620	63.3
Passivity phenomena	110	11.2	294	30.0
Delusions	478	48.8	876	89.4
Lack of insight	496	50.6	–	–
Restlessness/agitation	92	9.4	–	–
Bizarre behaviour	46	4.7	–	–
Restricted/blunted/inappropriate affect	282	28.8	–	–
Thought/speech disorder	126	12.9	–	–
Poverty of speech	88	9.0	–	–

(a) Within four weeks of the interview

The lifetime frequency of these symptoms is very similar in males and females (Figure 12.4).

Figure 12.4 All persons: Frequency of specific symptoms (lifetime) by sex



In the majority of the patients, the present state was dominated by 'positive' psychotic symptoms, such as delusions (48.8%) and hallucinations (36.1%). These two symptoms also occupied the highest rank when lifetime symptomatology is considered. Delusional ideas of persecution (threat of harm or injury) and reference (events, objects or people, radio or television messages having a special, usually ominous, significance referring to the patient) were particularly prominent. Similarly, the auditory hallucinations (voices) experienced by the majority of patients were typically of a derogatory, accusatory or persecutory content. Varying but generally high percentages of the patients had experienced loss of control or privacy over their own thoughts such as their thoughts being blocked, broadcast or taken away by some external agency, or alien thoughts being inserted into their minds. Almost one-third had at some time experienced a loss of control of their own volition such as being directly controlled by an outside force or agency (passivity phenomena). In the vast majority of interviews (91.2%), the rapport established between interviewer and respondent was rated as good (in the sense that the respondents freely gave a description of their experiences). Nonetheless, for 50.6% of the subjects, the experience of such 'positive' psychotic symptoms was accompanied by a compelling sense of reality resulting in a poor insight into their abnormal nature.

Affective symptoms were also common. Some 73.1% of participants had experienced depressed mood or dysphoria (defined as a persistent, pervasive and painful emotional state exceeding occasional sadness) at some stage (with 23.1% experiencing dysphoria currently), and 65.4% had experienced persistent loss of the capacity for enjoyment (anhedonia) over a lifetime (21.1% currently). A number of patients (29.1%) had been troubled by difficulties in concentration at some stage in the past with 6.4% currently experiencing difficulties. As many as 67.7% of the participants described having had thoughts or intentions of suicide at some time in their lives and 18.2% had had such thoughts in the previous four weeks. Abnormally elevated mood (mania or hypomania) was less common (34.8% lifetime and 5.5% present state).

The so-called 'negative' symptoms characteristic of schizophrenia and related disorders were less prominent on mental state examination (restricted or blunted affect was observed during the interview in 28.8% of participants, while less than 10% showed extreme poverty of thought or speech). Since such symptoms are rated on the basis of observation during the interview, that is, on time-limited samples of behaviour, these percentages are likely to underestimate the actual presence of negative symptoms. In fact, many of the behavioural impairments described in Section 14 and Tables 12.3 and 16.4 provide an indirect measure of the frequency of negative or deficit symptoms.

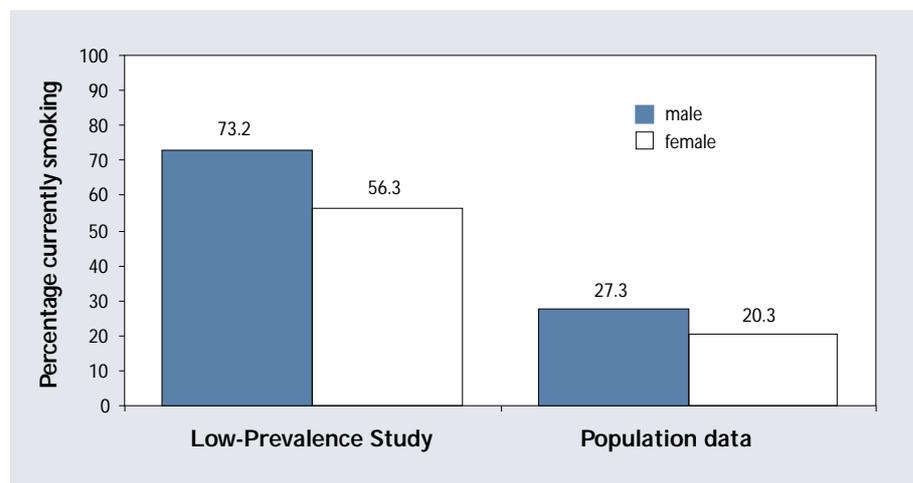
13 Psychoactive substance use

Use and abuse of substances acting on the central nervous system (other than medically prescribed drugs) is a common problem among people with psychotic illnesses.

13.1 Smoking

Tobacco is by far the most common substance of abuse, current smoking being reported by 73.2% of the men and 56.3% of the women in this study. This is markedly in excess of the prevalence of tobacco use in the general population of Australia (Figure 13.1).⁴¹ Only 16.5% of all the participants reported smoking fewer than 20 cigarettes per day; 22.3% reported smoking between 20 and 30; and 27.6% reported smoking 30 or more cigarettes daily.

Figure 13.1 All persons: Current tobacco use by sex



13.2 Alcohol use

The percentage of participants describing themselves as lifetime abstinent was 11.5%. Of those ever using alcohol, 42.3% of males and 30.5% of females (37.7% of all participants) had been drinking either daily or on several days a week during the year preceding the interview.

Problems experienced in relation to alcohol abuse included: work or family crises or trouble with police (28.9% of the total sample); physical health problems (18.1%); and self-injury (24.7%). A total of 328 participants (33.5%) scored positive on any two of the four screening items for harmful use of alcohol (derived from a well-validated screen: CAGE⁴²) and a lifetime diagnosis of alcohol abuse or dependence was made by the DIP/OPCRIT diagnostic algorithm in 30.0% of the sample.

13.3 Street drugs or non-prescribed medicaments

A total of 48.5% of the participants reported having used street drugs or non-prescribed medicaments on one or more occasions. In the order of frequency among those who had used such substances at all, the most commonly reported substances are: cannabis (72.2%); amphetamines (23.1%); LSD (20.2%); heroin (16.8%); and tranquillisers (13.5%). The use of cocaine, phencyclidine and inhalants or solvents is infrequent, with fewer than 10% of the participants ever having used one of them. Many of the participants (19.1%) had used more than one drug. A lifetime diagnosis of cannabis abuse was made in 25.1% of the total sample and a diagnosis of any other substance abuse or dependence in 13.2%. However, the percentages of the total sample describing daily or nearly daily use during the previous year varied considerably from 23.7% for cannabis to 5.8% for amphetamines; 4.5% for heroin; and 4.3% for tranquillisers. Work- or family-related problems, or contact with the police, as a result of drug use was described by 18.3% of the sample. Twelve per cent of the sample had wanted but felt unable to stop or cut down their drug use, or had experienced physical discomfort at attempts to do so.

13.4 Caffeine

Although 21.2% did not drink coffee at all, 24.5% of the participants reported having five to 10 cups of coffee daily and 6.1% described having more than 10 cups per day.

14 Social functioning, impairments and disability

14.1 Socio-economic characteristics

The variables current employment, occupational skill level, source of income and accommodation are used in this section to describe the socio-economic status of the 980 respondents at the point of the survey and the preceding 12 months.

The great majority of the participants (72.0%) were unemployed at the time of the interview and 58.3% were unable to describe any ‘main occupation’ during the previous 12 months. Of the 273 individuals (27.9%) of the sample who were in employment, only 96 (35.2%) had been working full-time throughout the previous 12 months. A small number (45 persons or 4.6% of the sample) were studying at the time of the interview and another small number (56 or 5.7%) referred to home duties as their main occupation. The majority (65.6%) of participants who had a full-time or a part-time job had been employed in occupations requiring either elementary or intermediate skill levels (Australian Standard Classification of Occupations⁴³ skill levels 4 and 5, including intermediate clerical, sales and service workers and production and transport workers, elementary clerical, sales and service workers and labourers and related workers). However, there were 55 individuals (20.1% of those in employment) who had been working at managerial, professional or associate professional levels, and another 39 (14.3% of those in employment) who were working in trades or in occupations at the advanced clerical and service level (Table 14.1). The great majority (83.2%) of those in employment had been working for an employer. Seventeen individuals (6.2%) had their own small businesses (no employees) and four (1.5%) owned businesses employing other people.

Table 14.1 Persons in full-time or part-time employment (n=273): Occupation by sex (per cent)

<i>Occupation (a)</i>	<i>Male</i>	<i>Female</i>	<i>Total</i>
Managers and administrators, professionals	9.2	19.0	12.8
Associate professionals	6.9	8.0	7.3
Tradespersons and related workers, advanced clerical and service workers	17.3	9.0	14.3
Intermediate clerical, sales and service workers, production and transport workers	17.9	31.0	22.7
Elementary clerical, sales and service workers, labourers and related workers	48.6	33.0	42.9
Total	100.0	100.0	100.0
Total persons	173	100	273

(a) grouped according to ABS Australian Standard Classification of Occupations (ASCO⁴³) skill levels

Only 152 individuals (15.5%) named wages from an employer or income from their own business as a main source of income. The majority (835 or 85.2% of the sample) were on a government pension or some form of social benefit. A total of 669 individuals (68.3%) in the sample were recipients of a disability pension.

Study participants lived in a variety of types of accommodation, and some had used more than one type within a short period of being interviewed. In the month prior to interview, 192 (19.6%) of the participants had stayed in an institution (hospital or nursing home), 133 (13.6%) had been accommodated in hostels, 28 (2.9%) in group homes, 25 (2.6%) in other supported housing, and 86 (8.8%) had been either homeless (without a fixed address) or had used crisis shelters, rooming houses, hotel or rented rooms. While 308 (31.4%) of the participants had resided in a rented home (public or private), only 142 (14.5% of the sample) had resided in their own home. A further 146 participants (14.9%) had stayed in a family home. See Table 11.4.

14.2 Social isolation

A high proportion (307 persons or 31.3%) of the participants in the survey were living alone, in single-person households. As observed earlier, 63.5% of participants (76.6% of men and 43.9% of women) were single and 20.6% were either divorced, separated or widowed. Only 15.9% (10.1% men and 24.6% women) were married or living with a de facto spouse. (See Table 11.2.) Although 33.1% (21.3% of men and 50.5% of women) had children, only 8.0% of the total sample (3.6% of men and 14.5% of women) had children under 18 years of age living with them at the time of the survey and 6.7% (2.6% of men and 12.9% of women) considered themselves to be the main carer for the children.

Only 91 participants (9.3%) had a person at home they could describe as a carer. The carer was most frequently the mother (41.8%) or a partner (24.2%). The extent of social isolation is further illustrated by the proportions of participants in the study who did not participate in ordinary home activities like sharing meals with others (47.1%); watching TV programs with others (40.0%); playing games (21.0%); or doing chores or errands for others (39.8%). Only 64.6% (61.9% of men and 68.5% of women) said they had daily or frequent face-to-face contact with any close relative over the past year (44.0% had such contacts with their parents, 30.3% with their siblings and 20.1% with their children). Although as many as 87.1% stated they knew people who they regarded as friends, 39.1% had no 'best friend' with whom they could share thoughts and feelings and 44.9% felt they needed 'good friends'. Of the 499 participants (50.9% of the total) who volunteered responses about their sex lives, 185 (37.1%) had had no sexual relationships because of lack of opportunity and 64 (12.8%) because of lack of interest or serious discord with the partner. While 30.1% (26.6% men and 35.4% women) said they had a satisfying sexual relationship during the last 12 months, another 20.0% (19.4% men and 21.0% women) were dissatisfied with the sexual relationships they had.

14.3 Impairment in activities of daily living

Impairments in daily life activities were rated on a 3-point scale (no dysfunction, obvious dysfunction and severe dysfunction) where each level was defined relative to the expected performance of a given activity by an 'average' person of the same sex and age group without a major mental or physical illness. Interviewers were trained to use specified probe questions and ask the respondent for examples of actual behaviour or relevant events occurring over the previous 12 months. They were required to use judgement (based on all information available) and to rate as impairments only deficits in performance that could be attributed to the effects of the illness.

Impairment in self-care (including personal hygiene, care for one's own appearance and efforts to keep physically fit) was rated as present in 29.8% of the sample. For 3.6% of participants, this amounted to marked self-neglect. Impairment in the maintenance of a general interest in the world around (including keeping up with the local and world news, sports, reading and hobbies) was present in 39.6%, including 9.7% in whom the loss of interest was severe.

Obvious or severe dysfunction in daily family or household activities (including cooking, cleaning, sharing meals and other tasks or behaviours involving interactions with other persons) was rated as present in 49.1% of those participants for whom participation in such activities was relevant (those living with a family or household) or in 25.8% of the total sample. Dysfunction in overall socialising outside the home (including items such as going out with friends or participating in group social activities in contrast to spending time alone) was present in 59.1% of the total sample and, in 57.6%, this restriction was rated as social withdrawal, that is, a tendency to self-isolation and avoidance of people. In a longer term perspective, the deficits in interpersonal functioning that many participants experienced tended to be stable. Thus, while some deterioration in interpersonal relationships in the previous year compared to prior years was rated in 29.2% of the total sample, improvement was described by 22.9% and no deterioration in the last year was rated in 46.1% of the sample.

14.4 Disability in major roles

Role disablement was assessed on a 3-point scale in a similar way to the assessment of impairments in activities of daily living. In addition, an estimate was made of the total number of weeks over the last year during which the subject had been incapacitated in a given role (weeks off role) and an attribution rating was made by the interviewer indicating the main reason for role incapacity.

Performance in a main occupational role (job, housework or studying) could be rated only for 374 (38.2%) of the participants who had carried out any such role in the previous year. Of these, 46.2% had experienced obvious or severe dysfunction.

Among the 273 participants (27.9%) who had any employment, 145 suffered an occupational dysfunction that accounted for 2,109 person-weeks off role (14.7%) out of the total 14,352 person-weeks during the year. In 69.6% of the 145, the time off role could be attributed to mental health problems only; in 20.7% to combined effects of mental and physical health problems; and in 8.9% to other reasons.

The 56 participants who had recorded home duties as their main occupation during the previous year had been incapacitated in this role for 8.6% of the corresponding total person-weeks for reasons of mental health (76.5%), combined mental and physical health problems (17.6%) or other reasons (2.9%).

Studying was rated as the main occupation for 46 participants who had accumulated 424 person-weeks off role during the year (17.7% of the corresponding total person-weeks). In 80.0% the main reason was mental health problems and in 20.0% combined mental and physical health problems.

It needs to be pointed out that a significant minority among the participants had experienced no dysfunction in their main occupational role performance during the year. Thus 89 (32.6%) of those in employment had not been incapacitated at all and another 41 (15.0%) had less than one week off role – giving a total of 47.6% (130 individuals) with little or no incapacitation. The

corresponding proportion among participants engaged in home duties was 35.7% (20 individuals) and among students 48.6% (17 individuals). The characteristics of these 167 high-functioning individuals with psychotic illness are compared with the characteristics of the total sample in Table 14.2.

Table 14.2 Frequency of specific symptoms in the high-functioning subgroup compared with the rest of the sample (per cent)

<i>Symptom</i>	<i>Census month sample subgroup, high occupational functioning N=167</i>		<i>Census month sample with psychosis, minus 167 'high functioning' cases N=813</i>	
	<i>Present state (a) %</i>	<i>Lifetime %</i>	<i>Present state (a) %</i>	<i>Lifetime %</i>
Dysphoria/depressed mood	18.0	75.4	24.5	72.6
Loss of pleasure	17.4	67.7	21.9	64.9
Suicidal ideation	16.8	68.9	18.5	67.4
Elevated mood	3.6	38.3	5.9	34.1
Irritability	2.4	22.8	6.4	27.9
Poor concentration	4.8	30.5	6.8	28.8
Hallucinations (any form)	25.1	74.3	38.4	72.7
Subjective thought disorder	25.1	64.7	36.0	63.0
Passivity	5.4	21.6	12.4	31.7
Delusions	32.9	89.8	52.0	89.3
Lack of insight	40.1	–	52.8	–
Restlessness/agitation	5.4	–	10.2	–
Bizarre behaviour	0.0	–	5.7	–
Restricted/blunted/inappropriate affect	21.6	–	30.3	–
Thought/speech disorder	9.0	–	13.7	–
Poverty of speech	4.8	–	9.8	–

(a) Within four weeks of the interview

These high functioning individuals have been further combined with two other groups of individuals with 'good outcomes', namely patients under the care of general practitioners or private psychiatrists and individuals not in current contact with services. This group of 446 cases is compared with the remaining cases on a number of variables in Section 19.

15 Service utilisation

15.1 Hospital admissions

Just over one-half (51.6%) of the participants had been admitted to an inpatient unit once or more during the year preceding the interview (admission was defined as at least an overnight stay) with 23.8% of participants reporting two or more admissions. Of the 506 patients admitted during the year, 232 or 45.8% had at least one involuntary admission. The annual number of voluntary and involuntary admissions is shown in Figure 15.1 and the type of inpatient admission is shown in Figure 15.2.

Figure 15.1 Persons with an inpatient admission in past year (n=506): Number of admissions by admission status

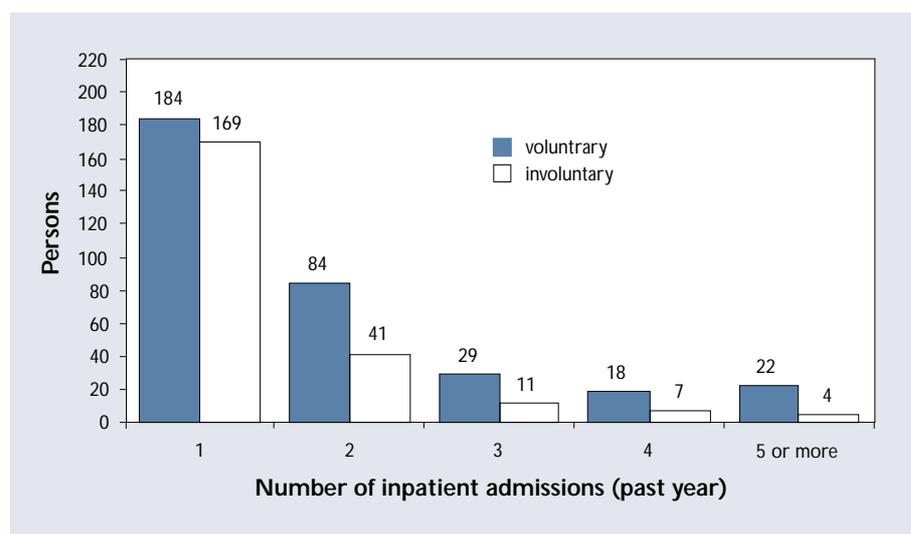
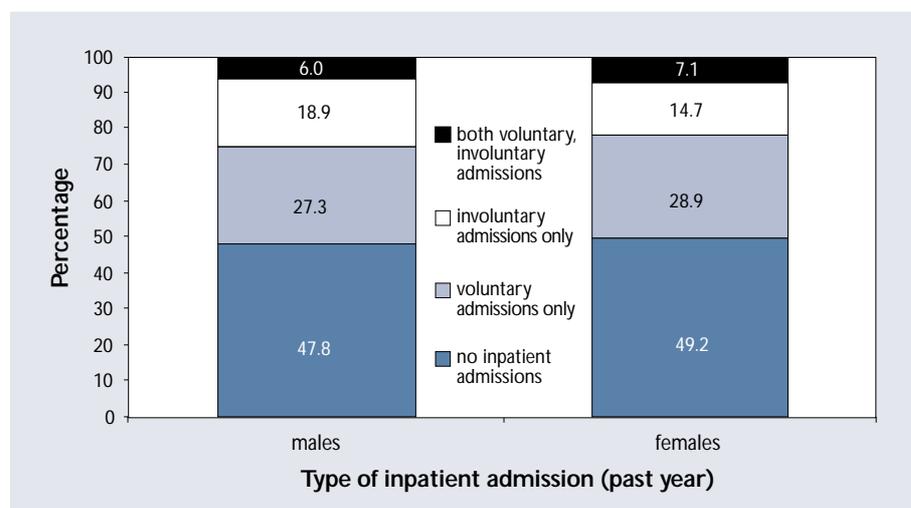


Figure 15.2 All persons: Type of inpatient admission (past year) by sex



The largest proportion of admissions had been to psychiatric inpatient units of public general hospitals (53.0% of all admissions) or public psychiatric hospitals (36.8% of all admissions); the percentage of all admissions to either of these facilities was 83.2%. Private facilities (psychiatric inpatient units, general hospitals and drug/alcohol units) accounted for only 7.5% of all admissions (Table 15.1).

Table 15.1 Persons with inpatient contact (n=506): Inpatient services used in past year (number, per cent)

<i>Inpatient service type (a)</i>	<i>N</i>	<i>%</i>
Either public psychiatric hospital or public psychiatric unit in general hospital	421	83.2
Public psychiatric unit in general hospital	268	53.0
Public psychiatric hospital	186	36.8
Private inpatient facilities	38	7.5
Total with any inpatient contact (% of all participants)	506	51.6

(a) An individual may have used more than one type of inpatient service in the year prior to interview

Figure 15.3a All persons: Total length of inpatient stays (past year) (persons)

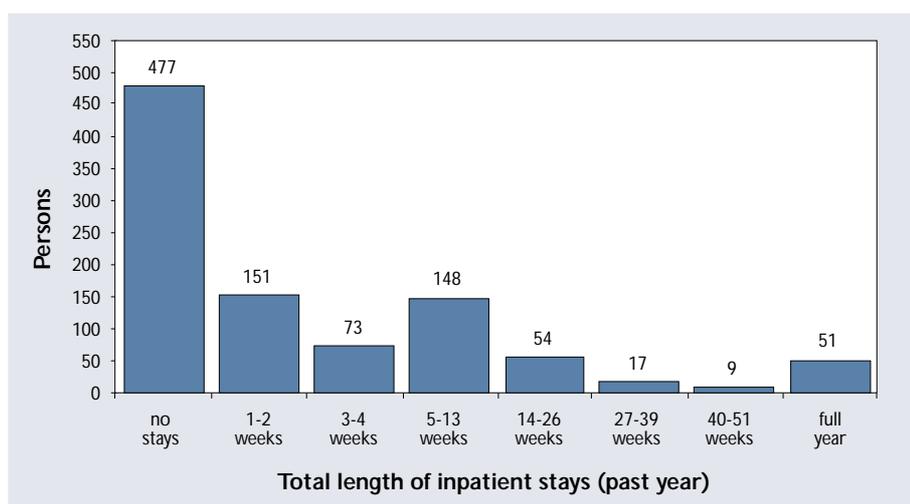
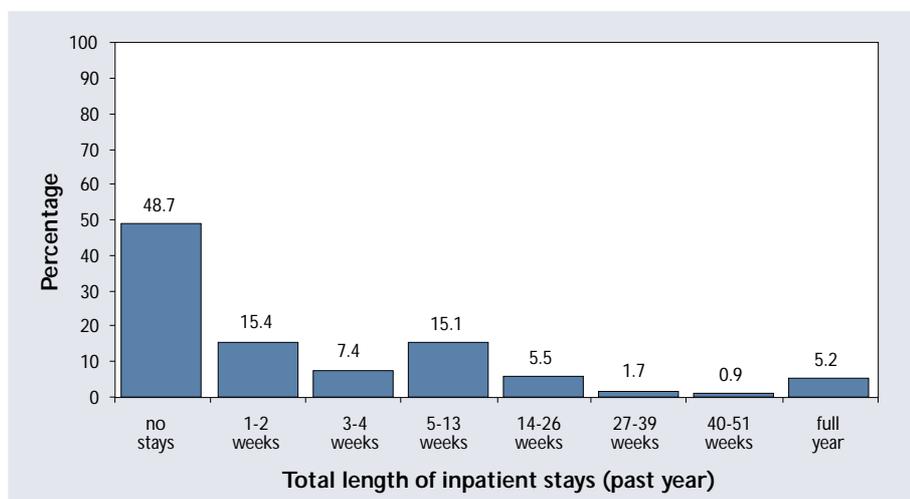


Figure 15.3b All persons: Total length of inpatient stays (past year) (per cent)



Of those admitted, 29.8% had spent a total of two weeks or less in hospital. However, 10.1% had been in hospital for a period of 12 months. The frequency distribution of inpatient weeks is plotted in Figures 15.3a and 15.3b. The mean length of stay was 13 weeks and the median was 6 weeks. The average length of stay varied by diagnostic classification: schizophrenia or schizoaffective disorder (mean 16 weeks; median 7 weeks); affective psychoses (mean 7 weeks; median 5 weeks); other psychoses (mean 8 weeks; median 4 weeks).

15.2 Use of emergency and crisis intervention services

A high proportion (43.9%) of the participants had had at least one contact with an emergency service during the preceding year, including 20.2% who had attended a general hospital emergency department only; 10.1% who had contacted a psychiatric emergency team only; and 13.6% who had made contacts with both hospital emergency departments and psychiatric emergency teams (Table 15.2). Of all individuals who had used emergency services, 37.0% pointed to a psychiatric problem as the main reason for contact while the same percentage reported a physical problem as the main reason for contact. Drug overdose, other self-inflicted harm, or alcohol- and drug-related problems were reported by 22.6%.

Table 15.2 All persons: Emergency and crisis intervention services used in past year (number, per cent)

<i>Emergency service type</i>	<i>N</i>	<i>%</i>
Emergency department in general hospital only	198	20.2
Psychiatric emergency team only	99	10.1
Both emergency department in general hospital and psychiatric emergency team	133	13.6
Total with any emergency service contact	430	43.9

15.3 Community and outpatient services

During the year preceding the interview, 60.1% of all participants had attended an outpatient or community mental health service with 43.1% of the total sample reporting frequent or regular visits. Of all the participants who had attended a community or other outpatient service, 63.7% made visits to a community mental health centre and 25.8% made visits to psychiatric outpatient departments in general hospitals (Table 15.3).

Table 15.3 Persons with outpatient contact (n=589): Outpatient services used in past year (number, per cent)

Outpatient service type (a)	N	%
Community mental health clinic	375	63.7
Psychiatric outpatient clinic in general hospital	152	25.8
Outpatient clinic in public psychiatric hospital	15	2.5
Private outpatient facility	11	1.9
Outpatient (non-psychiatric) clinic in public general hospital	10	1.7
Public drug and alcohol outpatient clinic	6	1.0
Total with any outpatient contact (% of all participants)	589	60.1

(a) An individual may have used more than one type of outpatient service in the year prior to interview

The number of visits made by those attending outpatient or community mental health services in the course of a year is shown in Figures 15.4a and 15.4b. The mean number of attendances was 17 and the median was 12. The average number of visits varied by diagnostic classification: schizophrenia or schizoaffective disorder (mean 17; median 12); affective psychoses (mean 16; median 10); other psychoses (mean 18; median 12).

Figure 15.4a All persons: Total number of contacts with outpatient services (persons)

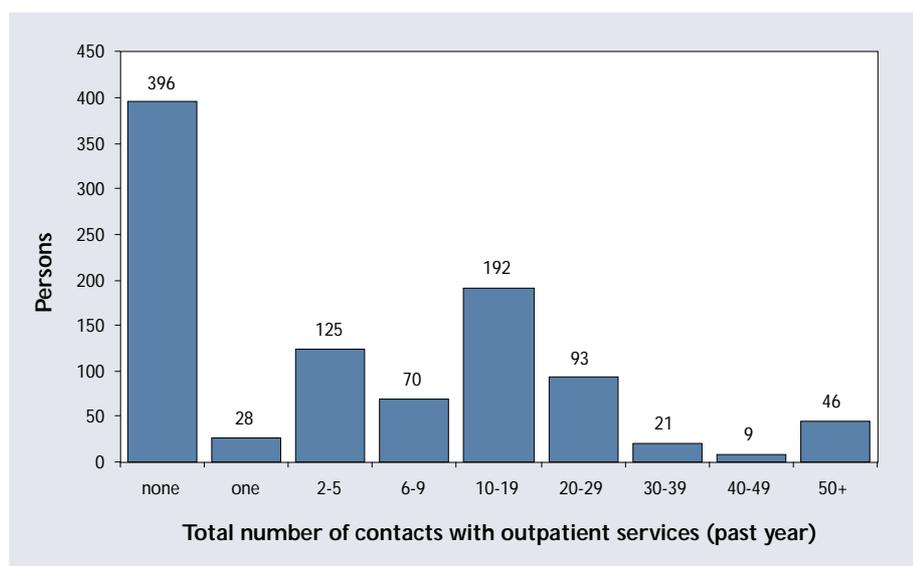
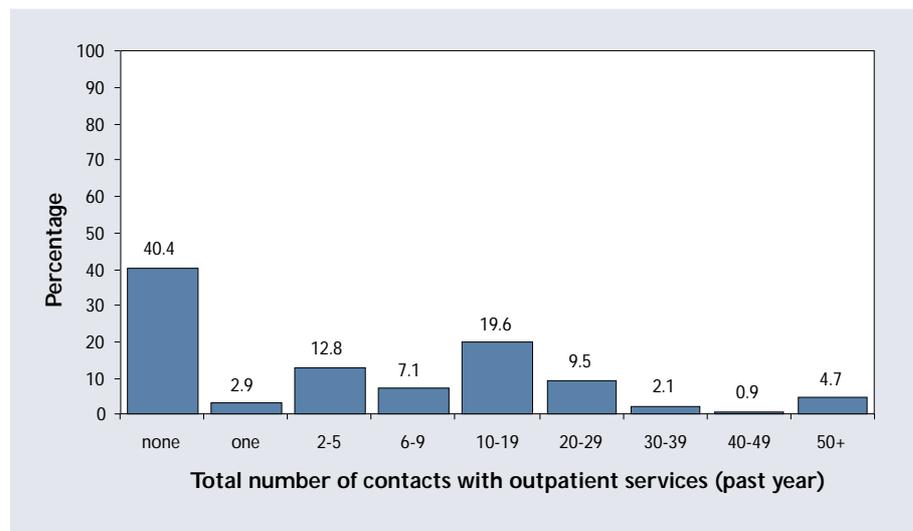


Figure 15.4b All persons: Total number of contacts with outpatient services (per cent)



The majority (551 respondents or 56.2% of the interviewed sample) said they had a case manager in the community team who was responsible for their care. The case manager was a nurse in 43.7% of instances and a social worker in 21.6%. Less commonly, the case manager was a medical officer (12.9%) or a psychologist (9.3%). A high proportion of the participants who had attended an outpatient or community clinic (90.0% of those attending) said that the health professional they saw most often when attending was a psychiatrist or other medical officer (Table 15.4).

Table 15.4 Persons with outpatient contact (n=589): Health professional most commonly seen at outpatient services in past year (number, per cent)

Health professional seen (a)	N	%
Psychiatrist or other medical officer	530	90.0
Nurse	198	33.6
Social worker	95	16.1
Psychologist	75	12.7
Occupational therapist	46	7.8
Drug and alcohol counsellor	5	0.8
Total with any outpatient contact (% of all participants)	589	60.1

(a) An individual may have seen more than one type of health professional at outpatient services in the year prior to interview

15.4 General practitioners, private psychiatrists and other specialists

A high proportion (797 respondents or 81.3% of the sample) had seen a general practitioner at least once during the past year. The mean number of visits made was 12 and the median was 5. The frequency of such visits is shown in Figures 15.5a and 15.5b. Private psychiatrists were seen at least once during the year by 239 participants (24.4%). The majority of them (154 persons) had made multiple (6 or more) visits. Only a small percentage (6.6%) of the sample had made visits to private psychologists. See Table 15.5.

Table 15.5 All persons: Health professionals seen outside of in- and outpatient services (number, per cent)

<i>Other health professional seen (a)</i>	<i>N</i>	<i>%</i>
General practitioner	797	81.3
Private psychiatrist	239	24.4
Medical, surgical specialist	224	22.9
Private psychologist	65	6.6

(a) An individual may have seen more than one type of health professional at outpatient services in the year prior to interview

Figure 15.5a All persons: Total number of contacts with general practitioner (persons)

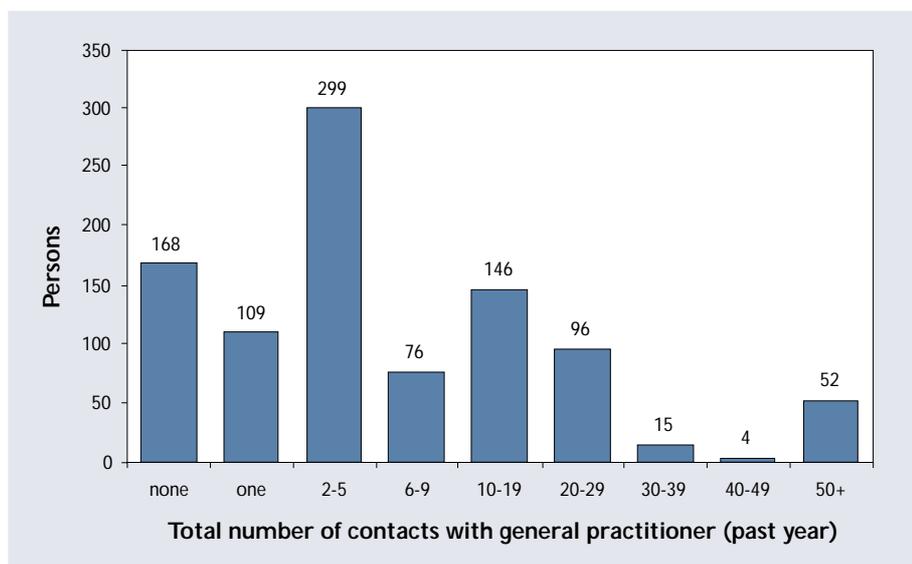
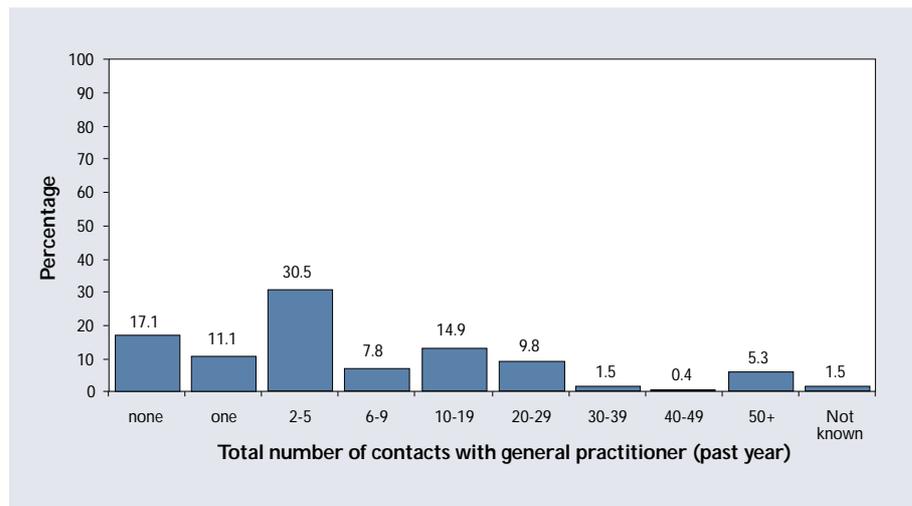


Figure 15.5b All persons: Total number of contacts with general practitioner (per cent)



The proportion of respondents who had private health insurance at the time of the interview was 13.2%, considerably lower than the national average of 31.9% for hospital insurance and 31.6% for ancillary insurance.⁴⁴

15.5 Services received in the past year

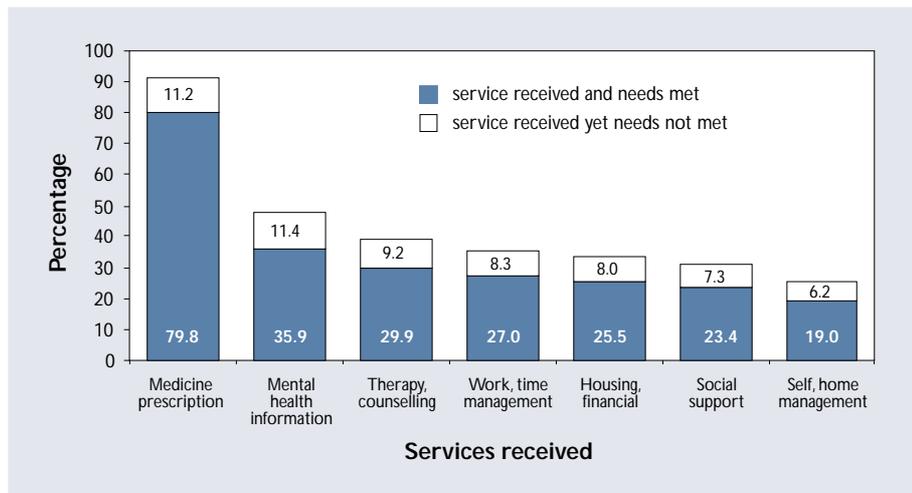
Respondents were asked whether, on one or more occasions during the year, they had received any number out of seven specified services. They were also asked whether the service provided adequately met their needs. The responses are presented in Table 15.6 and Figure 15.6.

Table 15.6 All persons: Specific services received and adequacy of service provided (per cent)

<i>Specific services received (a)</i>	<i>Received service %</i>	<i>Needs met, if service received %</i>
Medicine prescription	91.0	87.7
Provision of mental health information	47.3	75.9
Therapy, counselling	39.1	76.5
Help improving work skills, time management skills	35.3	76.6
Guidance in management of housing, financial matters	33.5	76.2
Social support	30.7	76.3
Advice on managing self and taking care of home	25.2	75.3

(a) An individual may have received more than one type of service in the year prior to interview

Figure 15.6 All persons: Specific services received and adequacy of service provided



Medication prescription was the service most frequently provided (91.0%) while help with self-care was the least frequently provided (25.2%). Psychotherapy, cognitive-behavioural therapy or counselling were identified as a service provided for 39.1% of the participants. The prescribing of medication was not only the most frequently provided service: it was a service that adequately met the needs of a greater proportion of the sample using the service (87.7%) than any other service. In contrast, the remaining services were perceived as less than adequate by an almost invariable proportion of about one-quarter of the participants.

The percentages of participants who had received other medical or dental examinations or care during the year are shown in Table 15.7.

Table 15.7 All persons: Other medical and dental services accessed in past year (number, per cent)

Other medical, dental services accessed (a)	N	%
Blood test	766	78.2
Physical examination by medical practitioner	743	75.8
Dental examination	455	46.4
X-ray examination	404	41.2
Ophthalmological examination	334	34.1
Audiological examination	96	9.8

(a) An individual may have used more than one type of service in the year prior to interview

15.6 Rehabilitation and day hospital programmes

Participation in a rehabilitation or a day hospital programme during the previous year was reported by a small number (187 or 19.1%) of the respondents. Of these, only 62 (6.3% of the sample) had been involved for 6-12 months while 73 (7.4%) had attended for 2 months or less. The majority (113) of the users of day or rehabilitation services had been attending for up to 2 days per week and only 21 participants had been involved in programmes run over 5 days per week.

15.7 Assistance from governmental and non-governmental agencies

The participants were asked about services received in the previous 12 months from 13 types of agencies and organisations. They were also asked whether the services they had received adequately met their needs. The data are shown in Table 15.8.

Table 15.8 All persons: Agencies contacted and adequacy of service provided (per cent)

<i>Agencies contacted (a)</i>	<i>Contacted agency %</i>	<i>Needs met, if agency contacted %</i>
Commonwealth Employment Service	25.4	57.4
Commonwealth Department of Social Security	68.5	87.0
Other government department: Housing	24.5	70.8
Other government department: Legal aid services	14.9	62.3
Other government department: Community services	8.8	47.7
Other government department: Veteran Affairs	4.3	11.9
Local council	11.9	59.8
Community counselling services	12.8	64.0
Family Court counsellors	4.7	15.2
Ethnic services	5.8	36.8
Church	36.7	85.8
Mental health self-help organisations	17.3	72.9
Other community organisations including: Salvation Army, Red Cross, St Vincent de Paul etc.	25.8	88.5

(a) An individual may have contacted more than one agency in the year prior to interview

Three government agencies were among the most frequently sought sources of services. The Commonwealth Department of Social Security had provided assistance to 68.5% of the sample and 87.0% of those who had received these services felt that their needs had been adequately met. State housing services had been used during the year by 24.5% of the sample and 70.8% were satisfied with the service provided. Assistance from the Commonwealth Employment Service had been sought by 25.4% of the total sample and 57.4% of these participants felt that their needs had been adequately met. Other government agencies, including departments of community services, local councils, legal aid services, family courts, ethnic services and community counselling services had been used by smaller percentages of the respondents with varying levels of satisfaction/dissatisfaction. Notably, services or assistance provided by the churches or by various non-governmental agencies and self-help organisations had been relatively widely used, with high percentages of the users reporting that their needs had been adequately met.

16 Treatment

The great majority of the participants (86.2%) stated that in the previous month they had been taking medication prescribed by a doctor for their mental health problems (only medication prescribed for one month or more was coded). The vast majority of the respondents were able to identify the drugs they had been prescribed from a table listing both the generic and trade names of drugs. The reported frequency of use by class of medication is shown in Table 16.1 (although it should be noted that the interview did not aim to ascertain the actual adherence to the prescribed medication). ‘Typical’ anti-psychotic agents were being used by 54.4%, including 25.6% of the participants who were receiving injectable depot preparations. The share of the newer, so-called ‘atypical’ anti-psychotic drugs was 30.8%. Use of mood stabilisers such as lithium, carbamazepine or sodium valproate was reported by 24.3%. The percentage reporting the use of any antidepressants was 26.4%; the majority (19.3% of the total) had been prescribed selective serotonin reuptake inhibitors (SSRI) or reversible inhibitors of the monoaminoxidase (RIMA) class.

Table 16.1 All persons: Medication currently used (number, per cent)

<i>Class of medication (a)</i>	<i>N</i>	<i>%</i>
‘Typical’ anti-psychotic agents (any)	533	54.4
Oral preparations	386	39.4
Injectable depot preparations	251	25.6
‘Atypical’ anti-psychotic agents	302	30.8
Mood stabilisers	238	24.3
Benzodiazepines and related compounds	106	10.8
Antidepressants (any)	259	26.4
Selective serotonin reuptake inhibitors (SSRI), or reversible inhibitors of the monoaminoxidase (RIMA) class	189	19.3

(a) An individual may be using more than one class of medication

16.1 Perceived benefits and side effects of medication

Many participants (83.4%) felt that their psychotic symptoms responded to medication. At the same time, a comparably large proportion (63.2%) described themselves as impaired in their daily life due to side effects of treatment (28.7% felt moderately or severely impaired). The frequency of specific side effects described by the respondents is listed in Table 16.2. Dryness of mouth or hypersalivation (48.2%); drowsiness during the day (47.7%); inner restlessness (36.0%); tremor (34.9%); and inability to relax (31.9%) were the most common complaints. Unwanted tongue movements, an indicator of the presence of so-called tardive dyskinesia (a neurological movement disorder which tends to occur after prolonged use of ‘typical’ anti-psychotic drugs) were reported by 12.7% of the respondents.

Table 16.2 All persons: Side effects of medication currently used (number, per cent)

<i>Reported side effects (a)</i>	<i>N</i>	<i>%</i>
Dry mouth or excessive salivation	472	48.2
Drowsiness or sleepiness during the day	467	47.7
Feeling of inner restlessness	353	36.0
Hands, arms or legs shaking or trembling	342	34.9
Inability to relax	313	31.9
Inability to stand still	290	29.6
Muscles feeling stiff or tensed up	275	28.1
Trouble with eyesight	270	27.6
Slowing down of movements	244	24.9
Unsteadiness when standing or walking	210	21.4
Unwanted tongue movement	124	12.7
Difficulty swallowing	123	12.6
Shuffling along	105	10.7
Difficulty starting walking	97	9.9

(a) An individual may report more than one side effect

The number of side effects experienced in the month prior to interview by the 845 participants currently taking medication is tabulated in Table 16.3.

Table 16.3 Persons currently using medication (n=845): Number of side effects (number, per cent)

<i>Number of side effects</i>	<i>N</i>	<i>%</i>
No side effects	134	15.9
One	103	12.2
2-4	268	31.7
5-9	264	31.2
10-14	76	9.0
Total currently using medication for mental health problems	845	100.0

16.2 Quality of life of people with psychotic disorders

In the context of health research, the concept of quality of life usually refers to two alternative, or complementary, domains of assessment and measurement: the objective level of functioning (or impairment) and the subjective perception of interference (or lack of interference) of the symptoms of illness with basic feelings of life satisfaction, self-esteem and fulfilment. While there is no generally accepted solution to many of the psychometric problems inherent in quality of life evaluation (and no 'gold standard' instrument), there is agreement that measures of quality of life, with their emphasis on the person, provide an important, complementary perspective on the 'burden of illness'.

A number of items directly or indirectly related to the two domains of objective functioning and subjective perceptions were incorporated in the DIP interview. Some of these variables have already been referred to in various sections of this report. They include impairment in activities of daily life and disablement in social or occupational roles (due to the illness or to side effects of medication); aversive mood and feeling states or cognitions (described as psychopathological symptoms); and objective adversity associated with social isolation, marginalisation and socio-economic deprivation. A synopsis of the main findings related to these areas is presented in Table 16.4.

Table 16.4 All persons: Impairments, disabilities and lifestyle variables by sex (number, per cent)

	Male N=586		Female N=394		Total N=980	
	N	%	N	%	N	%
<i>Impairment and disability</i>						
Impairment in daily life due to side effects of medication	365	62.3	254	64.5	619	63.2
Serious impairment in social, occupational functioning (SOFAS)	312	53.2	146	37.1	458	46.7
Dysfunction in overall work performance in past year (if in employment, home duties, study)	96	49.2	77	43.0	173	46.3
Dysfunction in participating in household activities (if applicable)	143	50.5	110	47.4	253	49.1
Dysfunction in caring for self in past month	199	34.0	93	23.6	292	29.8
Dysfunction in maintaining interests in past month	246	42.0	142	36.0	388	39.6
Dysfunction in socialising in past year	369	63.0	210	53.3	579	59.1
Dysfunctional level of social withdrawal in past year	358	61.1	206	52.3	564	57.6
Dysfunction in maintaining intimate relationships in past year	259	44.2	124	31.5	383	39.1
Dysfunction in maintaining sexual relations in past year (if response to this item)	92	30.3	72	36.9	164	32.9
<i>Satisfaction</i>						
Mostly satisfied with current level of independence	326	55.6	257	65.2	583	59.5
Mostly satisfied with life as a whole in past year	245	41.8	184	46.7	429	43.8
<i>Other ('lifestyle')</i>						
History of alcohol abuse	227	38.7	67	17.0	294	30.0
History of cannabis abuse	194	33.1	52	13.2	246	25.1
History of other substance abuse	100	17.1	29	7.4	129	13.2
Attempted suicide, self-harm in past year	99	16.9	63	16.0	162	16.5
Felt unsafe in current locality in past month	101	17.2	49	12.4	150	15.3
Arrested in past year	83	14.2	17	4.3	100	10.2
Victim of violence in past year	107	18.3	65	16.5	172	17.6

The table also includes quality of life related items which have not been discussed earlier such as feeling unsafe in the residential locality; being a victim of violence; occurrence of self-harming behaviour; arrests and being charged with an offence. Overall 15.3% of participants described feeling generally unsafe in their present neighbourhood or locality, and 17.6% reported that they had been a victim of violence in the last 12 months. Of the 172 respondents reporting such incidents, 62.2% described having been physically assaulted (including 7.0% sexually assaulted). The remaining 37.8% referred to robbery incidents (4.7% of the total) or did not provide specific details of the offence.

Instances of deliberate, self-inflicted harm or overdose during the previous 12 months were reported by 16.5% of the participants (4.8% had three or more such episodes).

A total of 10.2% of the sample reported having been arrested at least once in the past year (2.9% had more than one arrest). In the respondents' own description, the charges were for non-violent offences in 33.0% of the instances and for violent offences in 10.0% of the instances. However, insufficient detail was provided at interview on 57.0% of the reported instances.

17 Perceived needs

In the 12 months prior to interview, a total of 461 participants (47.0% of the sample) had experienced a need for a particular kind of service but had been unable to access it. They were asked in an open-ended question at interview to specify the nature of the service and to note if availability and/or affordability were the reasons that their need for the service was unmet. Services for which there was an unmet need are shown in Table 17.1. For 251 of the 425 respondents who named a specific kind of service, the main concern related to the provision of mental health care, with access to treatment, continuity of care and the need for mental health information ranking highest in order of frequency with which the issue was raised. Unavailability of the service was the stated reason for the unmet need in 61.2% of the responses that recorded an unmet need relating to the provision of mental health services; inability to afford the service was the stated reason in 23.8% of the responses.

Table 17.1 All persons: Unmet need for services (number, per cent)

<i>Services for which an unmet need was reported (a)</i>	<i>N</i>	<i>%</i>
Mental health related services – any	251	25.6
Mental health related services – access to services, treatment	123	12.6
Mental health related services – continuity of care	94	9.6
Mental health related services – general	60	6.1
Mental health related services – information	27	2.8
Physical health related services	49	5.0
Finance related services	39	4.0
Services related to social relations	38	3.9
Work, education related services	37	3.8
Transport related services	36	3.7
Services related to living situation	35	3.6
Services related to legal, safety issues	31	3.2
Leisure, participation related services	29	3.0
Services related to family, parenthood issues	13	1.3

(a) An individual may report an unmet need for more than one type of service

18 Characteristics of special groups

In addition to the enumeration of individuals with psychotic disorders using ‘mainstream’ inpatient and outpatient services at the time of the census (70.1% of the 980 individuals identified in the census month and interviewed), the study targeted and recruited for assessment two other groups of people with psychoses that were of special interest as regards their characteristics and needs. First, there were those living on the margins of society or who could be classified as either homeless or of no fixed abode and who were not identified within other service settings (12.2% of the total interviewed sample). Secondly, there were those in the sole care of a general practitioner or private psychiatrist (17.7%). These two groups, though contrasting in many ways, were likely to have in common a less ‘typical’ pattern of mental health service utilisation compared to the majority of persons with psychotic illnesses in the community. In this section, the characteristics of these two groups are compared with those of the ‘mainstream’ treatment service users.

18.1 Homeless or marginalised people with psychotic disorders not identified within other service settings

This group, comprising 120 people (7 in the Australian Capital Territory, 40 in Queensland, 59 in Victoria and 14 in Western Australia) was identified through emergency hostels, shelters, charity organisations and similar welfare agencies. In Victoria, part of the sample was recruited for interview through door-to-door screening in areas with boarding house type of accommodation.

In comparison with the ‘mainstream’ service users, the marginalised group with psychotic disorders had several relatively distinctive demographic characteristics (Table 18.1): a higher proportion of males (72.5% compared with 60.8% in the ‘mainstream’ group); a higher proportion of single persons (71.7% compared to 63.3%); a higher percentage lacking school- or post-school qualifications (58.3% compared to 47.9%); and a lower percentage who had any history of employment in the previous 12 months (10.0% compared to 17.0%).

Table 18.1 All persons: Socio-economic and other characteristics mainstream and marginalised subsamples (per cent)

	<i>Subsample with psychosis identified in census month</i>	
	<i>Marginalised or homeless sample N=120 %</i>	<i>Sample identified in mainstream services N=687 %</i>
Male	72.5	60.8
Single, never married	71.7	63.3
Children	30.8	32.6
Children under 18 years of age living at home	3.3	8.2
Highest qualification: completed secondary schooling	18.3	18.2
No school or post-school qualification	58.3	47.9
Living alone (and not homeless/institutionalised for full 6 months prior to interview)	28.3	31.6
Working full-time, part-time in 12 months prior to interview	10.0	17.0

No major or consistent differences were apparent between the two groups with regard to either lifetime or current psychopathology, but the marginalised group tended to have more prominent thought and speech disorders, passivity experiences and subjective thought disorder (including the abnormal experience of having thoughts that are not their own, thoughts being inserted into their mind by some external agency, their own thoughts being directly accessible to others or thoughts being extracted from their mind). The percentage reporting such symptoms was 40.8% among the homeless or marginalised people compared to 34.5% among the ‘mainstream’ treatment service users (see Table 18.2). Generally, a higher percentage of the individuals in the marginalised group had experienced, in the four weeks prior to interview, symptoms from the 10 clusters tabulated in the top panel of Table 18.2 compared to the mainstream services group.

Table 18.2 All persons: Frequency of specific symptoms mainstream and marginalised subsamples (per cent)

Symptom	Subsample with psychosis identified in census month			
	Marginalised or homeless sample N=120		Sample identified in mainstream services N=687	
	Present state (a) %	Lifetime %	Present state (a) %	Lifetime %
Dysphoria/depressed mood	25.8	65.8	23.3	73.7
Loss of pleasure	23.3	57.5	21.3	66.1
Suicidal ideation	21.7	63.3	17.6	68.1
Elevated mood	3.3	22.5	6.4	37.3
Irritability	10.8	27.5	5.8	28.5
Poor concentration	8.3	20.8	6.7	30.4
Hallucinations (any form)	39.2	70.8	38.9	75.1
Subjective thought disorder	40.8	64.2	34.5	62.7
Passivity	15.0	26.7	11.2	31.0
Delusions	53.3	81.7	51.2	91.7
Lack of insight	54.2	–	52.5	–
Restlessness/agitation	11.7	–	9.3	–
Bizarre behaviour	2.5	–	5.8	–
Restricted/blunted/inappropriate affect	23.3	–	31.0	–
Thought/speech disorder	17.5	–	12.8	–
Poverty of speech	7.5	–	10.0	–

(a) Within four weeks of the interview

When the course of the psychotic disorders in the two groups was compared over the entire previous length of illness (Table 18.3), chronic unremitting illness with varying degrees of deterioration was more common among the marginalised group (54.2%) than among the ‘mainstream’ group (41.2%).

Table 18.3 All persons: Course of disorder mainstream and marginalised subsamples (per cent)

Course	Subsample with psychosis identified in census month	
	Marginalised or homeless sample N=120	Sample identified in mainstream services N=687
Single episode, good recovery	10.0	8.0
Multiple episodes, good recovery	18.3	21.3
Multiple episodes, partial recovery	17.5	29.5
Chronic, little deterioration	31.7	17.6
Chronic, clear deterioration	22.5	23.6
Total	100.0	100.0
Total persons	120	687

Thus, on several measures the homeless or marginalised people with psychotic disorders appeared to be more severely ill than the rest of the people with such disorders in the community. The high prevalence of alcohol and other substance abuse (45.8% with alcohol abuse and 21.7% with other substance abuse, compared to 29.0% and 13.2% respectively in the 'mainstream' group) is likely to be a major contributing factor to the severity and chronicity of psychotic symptoms in this group (Table 18.4).

Table 18.4 All persons: Impairments, disabilities and lifestyle variables mainstream and marginalised subsamples (number, per cent)

<i>Sample identified in mainstream services</i> N=687	<i>Subsample with psychosis identified in census month</i>			
	<i>Marginalised or homeless sample</i> N=120		<i>Sample identified in mainstream services</i> N=687	
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>
<i>Impairment and disability</i>				
Impairment in daily life due to side effects of medication	47	39.2	466	67.8
Serious impairment in social, occupational functioning (SOFAS)	82	68.3	324	47.2
Dysfunction in overall work performance in past year (if in employment, home duties, study)	15	48.4	128	49.6
Dysfunction in participating in household activities (if applicable)	21	42.0	195	55.1
Dysfunction in caring for self in past month	38	31.7	220	32.0
Dysfunction in maintaining interests in past month	51	42.5	277	40.3
Dysfunction in socialising in past year	71	59.2	418	60.8
Dysfunctional level of social withdrawal in past year	69	57.5	396	57.6
Dysfunction in maintaining intimate relationships in past year	43	35.8	285	41.5
Dysfunction in maintaining sexual relations in past year (if response to this item)	16	25.0	126	35.1
<i>Satisfaction</i>				
Mostly satisfied with current level of independence	69	57.5	396	57.6
Mostly satisfied with life as a whole in past year	49	40.8	291	42.4
<i>Other ('lifestyle')</i>				
History of alcohol abuse	55	45.8	199	29.0
History of cannabis abuse	31	25.8	192	27.9
History of other substance abuse	26	21.7	91	13.2
Attempted suicide, self-harm in past year	31	25.8	115	16.7
Felt unsafe in current locality in past month	22	18.3	93	13.5
Arrested in past year	25	20.8	73	10.6
Victim of violence in past year	37	30.8	117	17.0

Although the marginalised group had higher levels of impairment in social and occupational functioning, as a whole these people were no more disabled than the ‘mainstream’ group of patients with regard to everyday functioning including self-care, interests and socialising (Table 18.4). Compared to the ‘mainstream’ group, a markedly lower proportion among the homeless people with psychoses (39.2% compared to 67.8% among the ‘mainstream’ sample) described themselves as impaired by side effects of medication (probably due to less regular use). Also, smaller percentages among the homeless, compared to the ‘mainstream’ patients, reported dysfunction in intimate and sexual relationships. Their level of self-reported satisfaction with personal independence and life in general did not differ from that of the ‘mainstream’ patients (40.8% were ‘mostly satisfied with life as a whole’ during the past year, compared to 42.4% among the ‘mainstream’ sample). However, a considerably higher proportion of the homeless group had attempted suicide or inflicted self-harm; they were also more likely to have been victims of violence, or to have been arrested during the previous year.

Consistent with the overall way of life and concomitant circumstances, the rate of utilisation of both in-patient and outpatient mental health services by the homeless was much lower than that by the patients recruited through the census of the ‘mainstream’ services (Table 18.5). Thus, only 27.5% had been admitted as in-patients during the previous year (compared to 62.9% of the ‘mainstream’ group), and only 35.8% had received any outpatient mental health care (compared to 75.3% of the ‘mainstream’ group). However, a higher percentage of the homeless (50.8% compared to 47.6% of the ‘mainstream’ group) had used hospital emergency services, and also a higher percentage (85.8% compared to 76.7% of the ‘mainstream’ group) had seen a general practitioner at least once during the previous year.

Table 18.5 All persons: Contact with treatment services mainstream and marginalised subsamples (per cent)

	<i>Subsample with psychosis identified in census month</i>	
	<i>Marginalised or homeless sample N=120</i>	<i>Sample identified in mainstream services N=687</i>
<i>Contact with treatment services in past 12 months (a)</i>	<i>%</i>	<i>%</i>
Inpatient services	27.5	62.9
Outpatient services	35.8	75.3
Emergency services (any)	50.8	47.6
Psychiatric emergency services	14.2	29.4
General practitioner	85.8	76.7
Private psychiatrist	15.0	16.2
Currently using medication for mental health problems	57.5	90.4

(a) An individual may have contacted more than one treatment service in the year prior to interview

As regards other helping agencies, a high proportion of the marginalised group had used the services of the Commonwealth Department of Social Security services now provided through Centrelink. Predictably, a high percentage of the homeless people with psychoses had used welfare services provided by church organisations or other charitable agencies. Generally, more of the homeless or marginalised people perceived that their needs were not adequately met by the organisations they had contacted. This was particularly the case with government housing departments (50.0% reported unmet need) and various mental health self-help organisations (50.0% reported unmet need). On the other hand, they reported relatively high levels of satisfaction with the aid provided by church and charitable organisations. See Tables 18.6 and 18.7.

Table 18.6 All persons: Specific services received and adequacy of service mainstream and marginalised subsamples (per cent)

<i>Specific services received in past 12 months (a)</i>	<i>Subsample with psychosis identified in census month</i>			
	<i>Marginalised or homeless sample N=120</i>		<i>Sample identified in mainstream services N=687</i>	
	<i>Using</i>	<i>Needs not met if using</i>	<i>Using</i>	<i>Needs not met if using</i>
	<i>%</i>	<i>%</i>	<i>%</i>	<i>%</i>
Medicine prescription	90.8	21.1	90.0	12.1
Provision of mental health information	35.0	54.8	53.0	20.1
Therapy, counselling	27.5	45.5	40.2	22.1
Help improving work skills, time management skills	33.3	47.5	37.6	20.2
Guidance in management of housing, financial matters	43.3	42.3	34.6	19.7
Social support	30.0	55.6	33.9	18.9
Advice on managing self and taking care of home	28.3	41.2	25.5	24.6

(a) An individual may have received more than one type of service in the year prior to interview

Table 18.7 All persons: Agencies contacted and adequacy of service mainstream and marginalised subsamples (per cent)

<i>Agencies contacted in past 12 months (a)</i>	<i>Subsample with psychosis identified in census month</i>			
	<i>Marginalised or homeless sample N=120</i>		<i>Sample identified in mainstream services N=687</i>	
	<i>Contacted agency</i>	<i>Needs not met, if agency contacted</i>	<i>Contacted agency</i>	<i>Needs not met, if agency contacted</i>
	<i>%</i>	<i>%</i>	<i>%</i>	<i>%</i>
Commonwealth Employment Service	31.7	42.1	25.5	41.1
Commonwealth Department of Social Security	83.3	19.0	67.5	11.9
Other government department: Housing	28.3	50.0	25.9	26.4
Other government department: Legal aid services	25.0	36.7	15.0	35.0
Church	43.3	21.2	35.7	13.5
Mental health self-help organisations	18.3	50.0	18.9	22.3
Other community organisations including: Salvation Army, Red Cross, St Vincent de Paul etc.	45.0	14.8	25.5	9.7

(a) An individual may have contacted more than one agency in the year prior to interview

18.2 People with psychotic disorder under the sole care of a general practitioner or a private psychiatrist

A total of 173 people with psychotic disorders were recruited for interview through general practitioners and private psychiatrists. They were selected for study on the basis of being primarily or mainly under the care of a general practitioner or a psychiatrist in private practice. This group was characterised by a high proportion (53.2%) of females and of individuals who had been married (41.6%), many of whom had children living with them. A high proportion (60.1%) had some school or post-school qualification and a relatively high proportion (30.6%) had been working during the preceding 12 months. See Table 18.8.

Table 18.8 All persons: Socio-economic and other characteristics mainstream and private treatment services subsamples (per cent)

	<i>Subsample with psychosis identified in census month</i>	
	<i>Sample identified through private psychiatrists, GPs N=173</i>	<i>Sample identified in mainstream services N=687</i>
	<i>%</i>	<i>%</i>
Male	46.8	60.8
Single, never married	58.4	63.3
Children	36.4	32.6
Children under 18 years of age living at home	11.0	8.2
Highest qualification: completed secondary schooling	16.2	18.2
No school or post-school qualification	39.9	47.9
Living alone (and not homeless/institutionalised for full 6 months prior to interview)	32.4	31.6
Working full-time, part-time in 12 months prior to interview	30.6	17.0

There were no major differences between the patients in this sample and the ‘mainstream’ patient sample with regard to the lifetime occurrence of psychotic symptoms and the pattern of course (Tables 18.9 and 18.10). However, the patients under the care of general practitioners or private psychiatrists tended to have less severe current symptoms, as shown by the lower percentages exhibiting lack of insight, hallucinations and delusions, subjective thought disorder, blunted affect and poverty of speech.

Table 18.9 All persons: Frequency of specific symptoms mainstream and private treatment services subsamples (per cent)

Symptom	Subsample with psychosis identified in census month			
	Sample identified through private psychiatrists, GPs N=173		Sample identified in mainstream services N=687	
	Present state (a) %	Lifetime %	Present state (a) %	Lifetime %
Dysphoria/depressed mood	22.0	75.7	23.3	73.7
Loss of pleasure	19.1	68.2	21.3	66.1
Suicidal ideation	17.9	68.8	17.6	68.1
Elevated mood	3.5	33.5	6.4	37.3
Irritability	1.7	20.8	5.8	28.5
Poor concentration	4.0	29.5	6.7	30.4
Hallucinations (any form)	23.1	65.9	38.9	75.1
Subjective thought disorder	28.3	64.7	34.5	62.7
Passivity	8.7	28.3	11.2	31.0
Delusions	35.8	85.5	51.2	91.7
Lack of insight	40.5	–	52.5	–
Restlessness/agitation	8.1	–	9.3	–
Bizarre behaviour	1.7	–	5.8	–
Restricted/blunted/inappropriate affect	23.7	–	31.0	–
Thought/speech disorder	9.8	–	12.8	–
Poverty of speech	5.8	–	10.0	–

(a) Within four weeks of the interview

Table 18.10 All persons: Course of disorder mainstream and private treatment services subsamples (per cent)

Course	Subsample with psychosis identified in census month	
	Sample identified through private psychiatrists, GPs N=173	Sample identified in mainstream services N=687
Single episode, good recovery	9.2	8.0
Multiple episodes, good recovery	20.2	21.3
Multiple episodes, partial recovery	26.6	29.5
Chronic, little deterioration	22.0	17.6
Chronic, clear deterioration	22.0	23.6
Total	100.0	100.0
Total persons	173	687

Compared to the mainstream patient sample, the group identified through general practitioners and private psychiatrists tended to have less dysfunction in social roles and in daily functioning, and were less likely to have a history of psychoactive substance use, attempted suicide or self-harm, or to have been a victim of violence (though a higher percentage felt unsafe in their residential location). See Table 18.11.

Table 18.11 All persons: Impairments, disabilities and lifestyle variables mainstream and private treatment services subsamples (number, per cent)

	<i>Subsample with psychosis identified in census month</i>			
	<i>Sample identified through private psychiatrists, GPs N=173</i>		<i>Sample identified in mainstream services N=687</i>	
	<i>N</i>	<i>%</i>	<i>N</i>	<i>%</i>
<i>Impairment and disability</i>				
Impairment in daily life due to side effects of medication	106	61.3	466	67.8
Serious impairment in social, occupational functioning (SOFAS)	52	30.1	324	47.2
Dysfunction in overall work performance in past year (if in employment, home duties, study)	30	35.3	128	49.6
Dysfunction in participating in household activities (if applicable)	37	33.3	195	55.1
Dysfunction in caring for self in past month	34	19.7	220	32.0
Dysfunction in maintaining interests in past month	60	34.7	277	40.3
Dysfunction in socialising in past year	90	52.0	418	60.8
Dysfunctional level of social withdrawal in past year	99	57.2	396	57.6
Dysfunction in maintaining intimate relationships in past year	55	31.8	285	41.5
Dysfunction in maintaining sexual relations in past year (if response to this item)	22	28.9	126	35.1
<i>Satisfaction</i>				
Mostly satisfied with current level of independence	118	68.2	396	57.6
Mostly satisfied with life as a whole in past year	89	51.4	291	42.4
<i>Other ('lifestyle')</i>				
History of alcohol abuse	40	23.1	199	29.0
History of cannabis abuse	23	13.3	192	27.9
History of other substance abuse	12	6.9	91	13.2
Attempted suicide, self-harm in past year	16	9.2	115	16.7
Felt unsafe in current locality in past month	35	20.2	93	13.5
Arrested in past year	2	1.2	73	10.6
Victim of violence in past year	18	10.4	117	17.0

Similarly to the homeless group, but for different reasons, this group made considerably less use of both in-patient and outpatient services than the ‘mainstream’ patients with psychoses (Table 18.12). In contrast to both the ‘mainstream’ patients and the homeless people with psychoses, the patients under the care of general practitioners or private psychiatrists also made less use of other governmental and non-governmental welfare organisations (Tables 18.13 and 18.14).

Table 18.12 All persons: Contact with treatment services mainstream and private treatment services subsamples (per cent)

	Subsample with psychosis identified in census month	
	Sample identified through private psychiatrists, GPs N=173	Sample identified in mainstream services N=687
Contact with treatment services in past 12 months(a)	%	%
Inpatient services	23.7	62.9
Outpatient services	16.8	75.3
Emergency services (any)	24.3	47.6
Psychiatric emergency services	7.5	29.4
General practitioner	96.5	76.7
Private psychiatrist	63.6	16.2
Currently using medication for mental health problems	89.6	90.4

(a) An individual may have contacted more than one treatment service in the year prior to interview

Table 18.13 All persons: Specific services received and adequacy of service mainstream and private treatment services subsamples (per cent)

	Subsample with psychosis identified in census month			
	Sample identified through private psychiatrists, GPs N=173		Sample identified in mainstream services N=687	
	Using %	Needs not met if using %	Using %	Needs not met if using %
Specific services received in past 12 months (a)				
Medicine prescription	95.4	7.3	90.0	12.1
Provision of mental health information	33.5	27.6	53.0	20.1
Therapy, counselling	42.8	18.9	40.2	22.1
Help improving work skills, time management skills	27.7	20.8	37.6	20.2
Guidance in management of housing, financial matters	22.0	23.7	34.6	19.7
Social support	18.5	18.8	33.9	18.9
Advice on managing self and taking care of home	22.0	10.5	25.5	24.6

(a) An individual may have received more than one type of service in the year prior to interview

Table 18.14 All persons: Agencies contacted and adequacy of service mainstream and private treatment services subsamples (per cent)

Agencies contacted in past 12 months (a)	Subsample with psychosis identified in census month			
	Sample identified through private psychiatrists, GPs N=173		Sample identified in mainstream services N=687	
	Contacted agency %	Needs not met, if agency contacted %	Contacted agency %	Needs not met, if agency contacted %
Commonwealth Employment Service	20.8	50.0	25.5	41.1
Commonwealth Department of Social Security	61.8	12.1	67.5	11.9
Other government department: Housing	16.2	21.4	25.9	26.4
Other government department: Legal aid services	7.5	61.5	15.0	35.0
Church	36.4	11.1	35.7	13.5
Mental health self-help organisations	10.4	33.3	18.9	22.3
Other community organisations including: Salvation Army, Red Cross, St Vincent de Paul etc.	13.9	16.7	25.5	9.7

(a) An individual may have contacted more than one agency in the year prior to interview

18.3 Comparison between the three census month subsamples

Some of the most marked differences between the three subsamples identified in the census are for ‘lifestyle’ variables including substance abuse, criminal offending and criminal victimisation. The group of marginalised people (outside of standard treatment services) reported a much higher frequency of alcohol abuse (45.8% compared with 23.1% for private services and 29.0% for mainstream services), other substance abuse not including cannabis (21.7% compared with 6.9% for private services and 13.2% for mainstream services), arrests in the past year (20.8% compared with 1.2% for private services and 10.6% for mainstream services), and violent victimisation in the past year (30.8% compared with 10.4% for private services and 17.0% for mainstream services). Equally noteworthy are the relatively low frequencies recorded for the group in private treatment services for all these lifestyle variables except for a lifetime history of alcohol abuse.

The three subsamples had different patterns of treatment service utilisation over the 12 months prior to interview (see Tables 18.5 and 18.12). To a large extent, these reflect the different recruitment sources of the three groups. Thus the mainstream services group had the highest percentage of patients using inpatient and outpatient services while the private treatment services group had the highest percentage in contact with general practitioners and private psychiatrists. Services most frequently used by the group outside of standard treatment services and living ‘on the margins’ at the time of the census were emergency services (which were not restricted to mental health related emergencies) and general practitioner services. The recorded use of inpatient and outpatient services by this group is partly due to recent contact with these treatment services between recruitment and interview, although a number of these individuals had been in contact with services prior to the census.

A number of important findings emerge from the comparison of subgroups within the census sample including the high rate of current symptomatology in the marginalised group that was outside standard treatment services. This is in contrast with their slightly lower rate for lifetime

symptomatology. It would appear that the group outside standard treatment services is currently less well than the group in mainstream treatment services despite a somewhat better lifetime symptom profile. This suggests that treatment programs are, at least to some extent, effective in ameliorating the symptoms of psychosis. In addition, the outside treatment services group is considerably more exposed to the risks of alcohol and drug abuse, criminal offending, violent victimisation as well as suicide and serious self harm. While the proportion of women within each subsample may be contributing to some of the differences found, this does not appear to be a large factor, particularly for the lifestyle variables.

The substantial differences found in the profiles of these three groups of individuals with psychosis highlight the need for policy makers to develop differentiated intervention strategies for psychosis depending on the target population.

18.4 People with psychosis and previous contact with services but no contact during the census month

Enumeration of the people with psychotic disorders based on service contacts during a census month is likely to miss individuals with a psychotic disorder who rarely use services or who have completely dropped out of service contact. It is important to know the characteristics of such low-intensity service users: do they represent a subgroup of people with severe illnesses who, for some reason, have drifted away from service provision? Or are they mainly individuals who have reduced or ceased their contacts with services because of a relatively good outcome and recovery? How many of them are actually receiving care from sources other than the mainstream public services?

To answer these and related questions, an additional sample of individuals with psychotic disorders was recruited and interviewed with the DIP. This sample was drawn by searching the registries of the hospitals and clinics participating in the study for any persons who had a diagnosis of schizophrenia (ICD-9 295.0-295.9); paranoid states (297.0-297.9) or other nonorganic psychosis (298.3, 298.4, 298.8, 298.9) made and recorded at some time in the past but who had not appeared on service records during the census month. Records were selected for inclusion in the study if the last contact with services had been within three years of the census.

Contact was attempted with a total of 801 individuals who were not in contact with services in the census month but who had had some contact within three years of the census and who met the eligibility criteria. Of these, 655 could not be interviewed for a range of reasons including inability to trace, refusal to participate, and ill-health at the time of contact. The total number interviewed was 146 of whom 98 had been in contact with services within 11 months of the census, but not in the census month, and 48 had been in contact with services up to three years prior to census month but not in the 11 months preceding census nor in the census month. Because of the difficulty in tracing individuals in this group and the high attrition rate, the sample of cases in contact with services in the period preceding census month cannot be regarded as representative of all persons meeting the sample criteria. See Table 8.1.

The 146 low-intensity service users were compared with a subset of the census month sample that included those 687 individuals (out of the total 980) who had been receiving care from the same mainstream services.

In terms of diagnostic distribution (research diagnosis based on DIP/OPCRIT), the two groups were very similar, with the exception of the lower proportion of bipolar disorder and mania

among the out-of-contact group (Table 18.15). The latter was most likely due to the exclusion of the ICD-9 category of manic-depressive psychosis from the search of the registries since it was likely to contain many cases with mood disorder who did not have psychotic symptoms.

Table 18.15 All persons: ICD-10 diagnostic classification by census month status (per cent)

<i>ICD-10 classification</i>	<i>Sample with psychosis, prior contact with mainstream services (inpatient, outpatient) but no contact in census month</i>	<i>Sample with psychosis, identified in mainstream services (inpatient, outpatient) in census month</i>
Schizophrenia	56.8	53.4
Schizoaffective disorder	11.6	11.5
Bipolar disorder, mania	6.2	12.4
Depressive psychosis	6.8	6.7
Other psychosis	15.8	13.2
Did not meet criteria for psychosis	2.7	2.8
Total	100.0	100.0
Total persons	146	687

In terms of lifetime symptom profiles, the two groups did not differ significantly from one another (except for the lower frequency of hypomanic symptoms in the out-of-contact group). However, they differed markedly with regard to present state symptoms (last month) with generally lower levels of symptomatology in the out-of-contact sample compared with the mainstream services group. See Table 18.16.

Table 18.16 All persons: Frequency of specific symptoms by census month status (per cent)

<i>Symptom</i>	<i>Sample with psychosis, prior contact with mainstream services but no contact in census month</i>		<i>Sample with psychosis, identified in mainstream services in census month</i>	
	<i>N=146</i>		<i>N=687</i>	
	<i>Present state (a)</i>	<i>Lifetime</i>	<i>Present state (a)</i>	<i>Lifetime</i>
	%	%	%	%
Dysphoria/depressed mood	15.8	74.0	23.3	73.7
Loss of pleasure	13.7	65.8	21.3	66.1
Suicidal ideation	11.6	62.3	17.6	68.1
Elevated mood	2.7	27.4	6.4	37.3
Irritability	3.4	17.1	5.8	28.5
Poor concentration	4.1	20.5	6.7	30.4
Hallucinations (any form)	27.4	74.0	38.9	75.1
Subjective thought disorder	24.0	60.3	34.5	62.7
Passivity	6.2	20.5	11.2	31.0
Delusions	39.0	91.1	51.2	91.7
Lack of insight	54.8	–	52.5	–
Restlessness/agitation	6.8	–	9.3	–
Bizarre behaviour	4.1	–	5.8	–
Restricted/blunted/inappropriate affect	24.0	–	31.0	–
Thought/speech disorder	7.5	–	12.8	–
Poverty of speech	4.8	–	10.0	–

(a) Within four weeks of the interview

Fewer people in the out-of-contact group had a history of alcohol, cannabis or other substance abuse. Also, lower percentages in the out-of-contact group had attempted suicide or other self-harm during the previous year, had been arrested, or had been victims of violence (Table 18.17).

Table 18.17 All persons: Impairments, disabilities and lifestyle variables by census month status (number, per cent)

	<i>Sample with psychosis, prior contact with mainstream services (inpatient, outpatient), no contact in census month</i> N=146		<i>Sample with psychosis, identified in mainstream services (inpatient, outpatient) in census month</i> N=687	
	N	%	N	%
<i>Impairment and disability</i>				
Impairment in daily life due to side effects of medication	71	48.6	466	67.8
Serious impairment in social, occupational functioning (SOFAS)	34	23.3	324	47.2
Dysfunction in overall work performance in past year (if in employment, home duties, study)	18	24.3	128	49.6
Dysfunction in participating in household activities (if applicable)	31	33.7	195	55.1
Dysfunction in caring for self in past month	31	21.2	220	32.0
Dysfunction in maintaining interests in past month	46	31.5	277	40.3
Dysfunction in socialising in past year	70	47.9	418	60.8
Dysfunctional level of social withdrawal in past year	73	50.0	396	57.6
Dysfunction in maintaining intimate relationships in past year	40	27.4	285	41.5
Dysfunction in maintaining sexual relations in past year (if response to this item)	19	20.7	126	35.1
<i>Satisfaction</i>				
Mostly satisfied with current level of independence	85	58.2	396	57.6
Mostly satisfied with life as a whole in past year	72	49.3	291	42.4
<i>Other ('lifestyle')</i>				
History of alcohol abuse	37	25.3	199	29.0
History of cannabis abuse	29	19.9	192	27.9
History of other substance abuse	11	7.5	91	13.2
Attempted suicide, self-harm in past year	11	7.5	115	16.7
Felt unsafe in current locality in past month	19	13.0	93	13.5
Arrested in past year	11	7.5	73	10.6
Victim of violence in past year	17	11.6	117	17.0

In terms of course of the psychotic disorder (Table 18.18), a single episode followed by good recovery was twice as common, while chronic course with severe deterioration was three times less common, in the out-of-contact group compared to the census sample. Between these two extremes, the percentages of participants reporting multiple episodes with either good or partial recovery and chronic course with little deterioration was similar for both groups.

Table 18.18 All persons: Course of disorder by census month status (per cent)

<i>Course</i>	<i>Sample with psychosis, prior contact with mainstream services (inpatient, outpatient), no contact in census month N=146</i>	<i>Sample with psychosis, identified in mainstream services (inpatient, outpatient) in census month N=687</i>
Single episode, good recovery	15.8	8.0
Multiple episodes, good recovery	22.6	21.3
Multiple episodes, partial recovery	34.2	29.5
Chronic, little deterioration	19.9	17.6
Chronic, clear deterioration	7.5	23.6
Total	100.0	100.0
Total persons	146	687

The out-of-contact group was further characterised by lower levels of impairment and disability (Table 18.17) and functioned better at home, at work and in relations with others. They were experiencing less impairment due to side effects of medication. On average, these people tended to report more satisfaction with their own independence and with life as a whole than the participants in the census sample but the difference was slight compared to the very considerable differences with regard to actual functioning in daily life.

It appears, therefore, that the out-of-contact sample included people with better outcomes in terms of symptomatology and psychosocial functioning. Since the diagnoses and past symptoms of the individuals within this sample were similar to those of the participants in the census month sample, a comparison between the two samples in terms of service use and other characteristics might highlight factors associated with better outcomes in people with psychotic disorders.

18.4.1 Service utilisation

Table 18.19 records service utilisation in the 12 months prior to interview. Since a proportion of the out-of-contact sample had actually re-established contact with the services in the interval between the census month and the point of interview (24.0% had an in-patient contact and 41.8% had one or more outpatient contacts), the two groups were compared in terms of mean rates of survival in the community.

Table 18.19 All persons: Contact with treatment services by census month status (per cent)

	<i>Sample with psychosis, prior contact with mainstream services (inpatient, outpatient), no contact in census month N=146</i>	<i>Sample with psychosis, identified in mainstream services (inpatient, outpatient) in census month N=687</i>
<i>Contact with treatment services in past 12 months (a)</i>	<i>%</i>	<i>%</i>
Inpatient services	24.0	62.9
Outpatient services	41.8	75.3
Emergency services (any)	34.9	47.6
Psychiatric emergency services	16.4	29.4
General practitioner	88.4	76.7
Private psychiatrist	30.8	16.2
Currently using medication for mental health problems	76.7	90.4

(a) An individual may have contacted more than one treatment service in the year prior to interview

It transpires from this analysis that few individuals within the out-of-contact group were entirely without service contacts. Rather, they could be characterised as less frequent service users, be it the use of inpatient, outpatient, or general emergency or psychiatric emergency services. However, in comparison to the census month sample, they tended to make more visits to general practitioners or private psychiatrists.

Somewhat lower percentages in the out-of-contact group were using the other services described in Tables 18.20 and 18.21 compared with the census month sample. However, those who did use these services were generally more satisfied. This was particularly so for those who had used government employment and housing services in the previous 12 months (Table 18.21). The out-of-contact sample was also more satisfied with the provision of services such as the provision of mental health information, therapy and counselling services and the prescription of medication (Table 18.20). Although only a few of the out-of-contact group had sought services on taking care of themselves and their home, over one third felt their needs had not been met by this service compared to a quarter of the census month sample that had used similar services.

Table 18.20 All persons: Specific services received and adequacy of service by census month status (per cent)

<i>Specific services received in past 12 months(a)</i>	<i>Sample with psychosis, prior contact with mainstream services (inpatient, outpatient), no contact in census month N=146</i>		<i>Sample with psychosis, identified in mainstream services (inpatient, outpatient) in census month N=687</i>	
	<i>Using</i>	<i>Needs not met if using</i>	<i>Using</i>	<i>Needs not met if using</i>
	<i>%</i>	<i>%</i>	<i>%</i>	<i>%</i>
Medicine prescription	77.4	6.2	90.0	12.1
Provision of mental health information	28.1	9.8	53.0	20.1
Therapy, counselling	31.2	10.9	40.2	22.1
Help improving work skills, time management skills	14.4	23.8	37.6	20.2
Guidance in management of housing, financial matters	18.5	14.8	34.6	19.7
Social support	14.4	19.0	33.9	18.9
Advice on managing self and taking care of home	8.9	38.5	25.5	24.6

(a) An individual may have received more than one type of service in the year prior to interview

Table 18.21 All persons: Agencies contacted and adequacy of service by census month status (per cent)

<i>Agencies contacted in past 12 months (a)</i>	<i>Sample with psychosis, prior contact with mainstream services (inpatient, outpatient), no contact in census month N=146</i>		<i>Sample with psychosis, identified in mainstream services (inpatient, outpatient) in census month N=687</i>	
	<i>Contacted agency</i>	<i>Needs not met, if agency contacted</i>	<i>Contacted agency</i>	<i>Needs not met, if agency contacted</i>
	<i>%</i>	<i>%</i>	<i>%</i>	<i>%</i>
Commonwealth Employment Service	24.7	27.8	25.5	41.1
Commonwealth Department of Social Security	54.8	11.3	67.5	11.9
Other government department: Housing	21.2	9.7	25.9	26.4
Other government department: Legal aid services	9.6	35.7	15.0	35.0
Church	37.0	14.8	35.7	13.5
Mental health self-help organisations	13.7	25.0	18.9	22.3
Other community organisations including: Salvation Army, Red Cross, St Vincent de Paul etc.	23.3	11.8	25.5	9.7

(a) An individual may have contacted more than one agency in the year prior to interview

19 Factors associated with differences in outcome

Analysis of predictors of outcome of the psychotic disorders was not among the main goals of the study. Such analysis would be appropriate in the context of a prospective study where a number of baseline characteristics of the sample are measured and recorded at the initial examination and the study population is followed up and re-examined after specified intervals. Nevertheless, a preliminary exploration was made of variables associated with differences in outcome that occurred within and between different subsamples in this study. Thus, a proportion (15.7%) of the people who had contacts with the 'mainstream' services during the census month gave a history of regular, uninterrupted employment during the preceding 11 months and could be considered high-functioning with regard to occupational adjustment. Even higher proportions (between one-quarter and one-third) of the participants who were under the care of private practitioners and/or had no service contacts during the previous 3 years had similar employment history suggestive of good outcome. To obtain a subsample of good outcome cases sufficiently large for analysis, the high-functioning participants from the 'mainstream' sample were grouped together with the patients under the care of general practitioners or private psychiatrists and with the individuals not in current contact. This group of 446 persons with good outcome (in terms of occupational functioning) was compared with the remaining 680 cases on a number of variables related to their premorbid adjustment as well as variables describing their illness history. These variables were selected on grounds of previous reports in the literature about their association with differences in outcome in psychotic disorders. Comparisons were made by calculating odds ratios (OR) and their corresponding 95% confidence intervals (CI). A difference between the groups compared is accepted as significant if the confidence interval of the OR does not contain unity.

The results are summarised in Tables 19.1 and 19.2. Of the 14 variables on which the good and poor outcome groups were compared, 9 showed significant differences between the groups. The good outcome cases tended more often to be female (OR 1.6) and to have the onset of their psychotic illnesses later, at age 34 or older (OR 1.6). The good outcome cases had a history of good work adjustment (OR 1.5) and social adjustment (OR 1.5) before the onset of illness and were more likely (OR 1.7) to have no premorbid personality disorder. They had a higher educational achievement such as completed secondary school (OR 1.7) and individuals with a tertiary degree or diploma were more than twice as likely (OR 2.7) to have a better occupational outcome than those without school qualification. None of the particular psychotic symptoms experienced in a lifetime, nor the response of those symptoms to anti-psychotic medication distinguished clearly the two groups but the high-functioning individuals were significantly less likely to attract a 'dual diagnosis' of a substance abuse disorder.

Table 19.1 All persons: Selected socio-economic and premorbid variables 'good' outcome compared with 'other' outcome cases (per cent, odds ratio - 95% confidence interval)

	Subsample		'good' vs 'other' outcome Odds ratio (95% CI)
	'good' outcome cases N=446	'other' outcome cases N=680	
Sex			
Male	52.2	63.2	reference category
Female	47.8	36.8	1.6 (1.2, 2.0)
TOTAL (%)	100.0	100.0	
Highest educational qualification			
No school qualification	38.1	52.5	reference category
Secondary school	20.9	17.2	1.7 (1.2, 2.3)
Trade or other certificate	21.7	18.7	1.6 (1.2, 2.2)
Tertiary degree, diploma	17.0	8.7	2.7 (1.8, 4.0)
Other	2.2	2.9	1.0 (0.5, 2.3)
TOTAL (%)	100.0	100.0	
Premorbid work adjustment			
Good	74.7	66.0	1.5 (1.2, 2.0)
Poor	25.3	34.0	reference category
TOTAL (%)	100.0	100.0	
Premorbid social adjustment			
Good	72.2	63.2	1.5 (1.2, 2.0)
Poor	27.8	36.8	reference category
TOTAL (%)	100.0	100.0	
Premorbid personality disorder			
No	87.7	81.0	1.7 (1.2, 2.3)
Yes	12.3	19.0	reference category
TOTAL (%)	100.0	100.0	
Marital status			
Single, never married	59.4	64.0	reference category
Other	40.6	36.0	1.2 (0.9, 1.6)
TOTAL (%)	100.0	100.0	

Table 19.2 All persons: Selected symptoms 'good' outcome compared with 'other' outcome cases (per cent, odds ratio - 95% confidence interval)

	Subsample		'good' vs 'other' outcome Odds ratio (95% CI)
	'good' outcome cases N=446	'other' outcome cases N=680	
Age group at onset			
Under 20 years	31.6	34.3	reference category
20-34 years	52.0	54.4	1.0 (0.8, 1.4)
Over 34 years	16.4	11.3	1.6 (1.1, 2.3)
TOTAL (%)	100.0	100.0	
Relationship between psychotic and affective symptoms			
No co-occurrence	27.1	27.5	reference category
Psychotic symptoms predominate	31.2	33.5	0.9 (0.7, 1.3)
Balanced co-occurrence	11.9	12.4	0.98 (0.6, 1.5)
Affective symptoms predominate	29.8	26.6	1.1 (0.8, 1.6)
TOTAL (%)	100.0	100.0	
Systematisation of delusions – lifetime			
No	65.5	62.5	1.1 (0.9, 1.5)
Yes	34.5	37.5	reference category
TOTAL (%)	100.0	100.0	
Widespread delusions – lifetime			
No	55.4	50.9	1.2 (0.9, 1.5)
Yes	44.6	49.1	reference category
TOTAL (%)	100.0	100.0	
Psychotic symptoms respond to neuroleptics			
No response	14.6	17.4	reference category
Response	85.4	82.6	1.2 (0.9, 1.7)
TOTAL (%)	100.0	100.0	
History of alcohol dependence/abuse			
No	74.7	67.9	1.4 (1.1, 1.8)
Yes	25.3	32.1	reference category
TOTAL (%)	100.0	100.0	
History of cannabis dependence/abuse			
No	80.0	72.6	1.5 (1.1, 2.0)
Yes	20.0	27.4	reference category
TOTAL (%)	100.0	100.0	
History of other substance dependence/abuse			
No	90.8	85.4	1.7 (1.1, 2.5)
Yes	9.2	14.6	reference category
TOTAL (%)	100.0	100.0	

20 Strengths and limitations of the study

In comparison to other recent surveys of psychotic disorders conducted overseas, the present study has several advantages. First, it combines in a two-phase design an epidemiological census of treated psychotic morbidity with a clinical investigation of a sample drawn from the census. Second, the data collected on each person interviewed are more extensive than in most other studies and include not only basic demographic, diagnostic and clinical variables but also social functioning, activities of daily living, services and treatment received, and perception of quality of life and unmet need. Third, the multi-centre collaborative design of the study ensured that the sample of individuals with psychotic disorders assessed by interview was considerably larger than is usually the case in such research. These three features of the study, and especially the large sample size, provide reasonable assurance that its conclusions are valid.

However, as is often the case with epidemiological research into the mental disorders, any study design has to take into account numerous difficulties, including the low population prevalence and the logistic problems of detecting, recruiting and interviewing people with psychotic disorders. This necessitates a carefully considered trade-off between the objectives of the study (and these are usually more than one) and the development of a complex design to ensure that as many as possible of the objectives will be adequately met.

In planning this study, a decision was made to set the primary focus of the investigation on people with psychotic disorders who are using a range of services in defined geographical areas and to interview as many of them as feasible within the resources of the study in order to obtain a fuller picture than available until now of the multiple facets of their illnesses and social functioning. This meant selecting a catchment area and 'mainstream' service-based census sampling frame, rather than a general population sample, for identifying the main group of respondents. However, additional samples were drawn to ensure that subgroups of special interest – for example people under the care of private practitioners, homeless persons, and individuals who are no longer in contact with the services – were also represented in the total study population. Appropriate sampling schemes were put in place for these special groups but a number of factors that are difficult to control may have affected the extent to which these additional samples are representative. Certain assumptions that had to be made if the contribution of these particular groups to the prevalence rate of psychoses were to be estimated are stated in Appendix 1. Caution is advised, therefore, with regard to these three groups, in generalising the rates and proportions reported here to the respective totality of those populations.

A number of other constraints need to be stated. First, slightly over 50% of the persons who were screened at the mainstream services during the census month and found eligible for interview could not be interviewed for various reasons (listed in Table 8.1). The possibility that these non-respondents might differ from the persons successfully interviewed on a number of characteristics cannot be ruled out.

Secondly, the study sample is not representative of population groups such as the Aboriginal people or of any single group defined by ethnic or geographic origin. People of Aboriginal background have been included in the sample if they had been in contact with the services and met the general inclusion/exclusion criteria. Establishing the prevalence or the clinical and

social characteristics of psychotic disorders among the Aboriginal population of Australia was not among the objectives of the study (that would require a specially designed, carefully prepared investigation). The same consideration applies to other population groups, including immigrants.

Thirdly, the data on service utilisation and treatment are based on the participants' reports at interview and not on actual service records. While no reason exists to suspect a major discrepancy between such reports and actual service data, some variance due to inaccuracies of subjective recall could reasonably be expected. To the extent that this may have occurred, it is unlikely to have exerted a major distorting effect. A number of checks guarding against such distortion were built into the instrument and research procedure which required the interviewer to cross-examine many of the respondents' statements; for example, by asking for specific description or examples, and by using judgement in accepting and rating the participant's responses.

Lastly, the interview deliberately did not explore the important issue of adherence to the prescribed treatment. Inclusion of a proper inquiry into treatment adherence would exceed the time limits of the interview and might shift the focus of the relevant part of the interview away from the main goal of inventorying the treatments prescribed, exploring the respondents' experience and expectations with regard to treatment, and eliciting subjective accounts of attributed side effects.

21 Overview of results and conclusions

The first multi-centre collaborative study on psychoses in Australia

This is the first Australian collaborative study on psychotic disorders in which identical methods and instruments were applied simultaneously in four urban areas to determine the prevalence of such disorders, to obtain a clinical and sociodemographic profile of the people with psychotic illnesses and to examine the ways they access a variety of services. In addition to collecting detailed socio-demographic and clinical information by interviewing 1126 respondents, the study explored aspects of their quality of life and the perceived need for specific services and care. The study encompasses a range of psychotic disorders including schizophrenia and related conditions, delusional disorder, bipolar affective disorder (manic-depressive illness) and major depression with psychotic features. Common to this group of psychiatric disorders is the disturbance in the perception and interpretation of the surrounding world, the altered sense of self, and the consequent disorganisation of behaviour. These disturbances may be continuous or episodic and are manifested in symptoms such as delusional beliefs, hallucinations and disordered speech and thought. Psychotic disorders occur in all populations and cultures, and studies by the World Health Organization⁹ have shown that their incidence (the number of new cases appearing in a given population over a defined period of time) is similar in different parts of the world.

The study design combined an epidemiological census of psychoses with an in-depth clinical study in which a large sample of persons with psychotic illnesses were interviewed.

The study was designed as a two-phase survey. In the first phase, an epidemiological census of people with psychotic illnesses was carried out by screening all contacts made during one month with mental health and other services in defined catchment areas in the Australian Capital Territory, Queensland, Victoria and Western Australia. In the second phase, a sample of 980 individuals who had been in contact with the services during the census month, and a further sample of 146 individuals who had been in contact with services in the three years prior to census but not in the census month, were interviewed. The assessment at interview comprised the use of a semi-structured interview schedule, the Diagnostic Interview for Psychoses (DIP) which is a systematic inquiry into the subject's relevant demographic characteristics, symptoms, functioning in daily life, treatment and use of various services, satisfaction and perception of needs. The DIP covers both present and past symptoms and is linked to a computer diagnostic algorithm (OPCRIT) which generates a diagnostic classification according to several internationally used criteria including ICD-10 and DSM-III-R.

It should be noted that the main focus of the study was on the treated point prevalence – in other words on the number, characteristics and experience of people currently using the 'mainstream' mental health services. However, the study also addressed several other important issues. First, it examined a sample of people with psychotic disorders who were predominantly or exclusively

under the care of general practitioners or private psychiatrists to determine their socio-demographic and clinical characteristics. Secondly, the research teams screened a number of refuges, night shelters and boarding houses and interviewed some 120 individuals at different stages in the transition to homelessness. It was important to estimate the prevalence of psychoses among people of marginalised social status and to assess their needs. Thirdly, samples were drawn from hospital and clinic records, of persons who had a history of previous treatment of a psychotic illness but had made no contact with the service during the year preceding the census. The aim was to determine whether the lapse in service contact was associated with a worsening or improvement of mental state.

The study resulted in a large and informative database.

Notwithstanding the constraints discussed in the preceding section, the study provided an overview of the main categories of people with psychotic disorders in urban Australia and generated an extensive database of their clinical and social characteristics. The present report documents the main findings and draws the general picture using descriptive statistics. A series of publications focusing more analytically on specific details of the picture is in preparation by the research teams.

The point prevalence (one month) of psychotic disorders in the adult population of urban areas in Australia is in the range of 4 to 7 per 1000 with a weighted mean of 4.7 per 1000.

With all the caution required when drawing general conclusions from a study of a complex design, the outline of the picture is as follows.

Between 3 and 5 adults (3 to 6 males and 2 to 4 females) per 1000 population at risk (age groups 18–64) have a psychotic disorder and are in treatment contact with a ‘mainstream’ mental health service at any time during a 30-day census period. Another 1 to 2 persons per 1000 population have psychotic disorders and are under the care of general practitioners or private psychiatrists during the same time period. A further 0.5 to 1.2 persons per 1000 have been in treatment contact during the 11 months preceding the census month but made no contact with the service during the census month. Thus, the estimate for the point (one month) prevalence rate is between 4 and 7 per 1000 adults for contact with any treatment service. Using a weighted mean, the estimate of the overall treated prevalence rate for contact with any service across the four sites within a one-month period is 4.7 per thousand (5.2 for males, 4.1 for females). The period (one-year) prevalence rate for contact with mainstream services only is between 3 and 6 per 1000 adults.

The rate of detected psychotic illness among the homeless people who are not regular users of the ‘mainstream’ mental health services is less than 0.3 per 1000 general population at risk, except at the Victorian site where the rate for this inner city catchment area is up to 1.3 per 1000. The latter finding confirms the results of other studies indicating a high prevalence of psychoses among the urban homeless people.

These findings about the prevalence of psychotic illness are in keeping with the results from epidemiological studies conducted in other populations with a demographic and socio-economic profile comparable to that of Australia (see Table 9.1).

Schizophrenia accounts for over 60 per cent of the prevalence of psychotic disorders.

From the point of view of classification, the largest diagnostic group is that of schizophrenia and schizoaffective disorder (62.4% of all psychoses according to ICD-10; 59.8% according to DSM-III-R). Affective disorders (bipolar mania and depressive psychoses) account for 19.5% (ICD-10) or 29.6% (DSM-III-R). The remaining disorders include delusional and acute transient psychoses, as well as a small percentage of cases which were in treatment but did not fully meet the research diagnostic criteria for a specific psychotic disorder. It should be noted that all diagnoses reported here are *research* diagnoses and not hospital diagnoses, i.e. they are: (i) based on a standardised interview; and (ii) derived by a computer algorithm which minimises the differences in the interpretation of symptoms and signs that may arise between different clinicians. Although such research diagnoses are not necessarily more valid than the diagnoses made by a skilled clinician, they follow explicit rules that are consistently applied across the patient sample and thus provide a valid basis for comparisons.

People with psychotic disorders carry a heavy burden of ill-health and disability.

One of the main conclusions of this study is that people with psychotic disorders carry throughout their lives an immense load of psychological ill health and social and economic disadvantage. These problems are manifested on several levels: (i) psychological and behavioural – in terms of experienced symptoms, their duration and extent of personality disorganisation and subjective distress; (ii) impairments and disabilities affecting their daily lives and compromising the achievement of educational, occupational and economic goals; (iii) enforced adoption of a dependent role of a ‘consumer’ of welfare and services. The data of the survey documenting and illustrating each one of these three levels of disadvantage are summarised below.

The symptoms of psychotic disorders are distressing and tend to persist or re-occur over long periods of people's lives.

The majority of the persisting psychotic illnesses, and especially schizophrenia, have their onset in late adolescence or early adulthood. The self-reported mean age at onset was 23.8 years in males and 24.8 years in females. At the point of the interview, the mean length of previous illness was 15.1 years. In a high proportion of the participants (47.6% of the males and 36.8% of the females) the course of the illness was continuous without remission of symptoms. In 43.3% of the males and 55.6% of the females the course consisted of multiple episodes of psychosis, with partial or good recovery between the episodes. By the time of the interview in this cross-sectional survey, 9.0% of the males and 7.6% of the females had experienced a single psychotic episode from which they had made a good recovery. The great majority of the participants (from 63.3% to 89.4%) had experienced in the past the cardinal symptoms of psychosis: hallucinations, delusions and subjective thought disorder (including the experience of their own thoughts being interfered with by some external agency). At interview, nearly one-half of the participants described delusional beliefs and over one-third reported hallucinations and subjective thought disorder (e.g. experience of their thoughts being interfered with). Loss of the ability to enjoy life (anhedonia), suicidal ideation and poor concentration were other frequent lifetime experiences and in nearly one-third there was evidence at interview of at least one negative symptom, such as affective blunting.

Males and females are similarly affected.

Although females tended to have more affective symptoms and a higher frequency of remissions than males, these differences were small and the burden of psychotic illness seems to affect equally the two sexes.

Co-morbid substance use disorder ('dual diagnosis') complicates the course of psychotic illness in a substantial proportion of cases.

An important finding was the high rate of use of street drugs or non-prescribed medicaments by people with psychotic disorders. As many as 48.5% reported use of psychoactive substances on one or more occasions. So-called 'dual diagnosis' (a primary diagnosis of psychotic disorder and a co-morbid diagnosis of a disorder due to substance use) was made in 25.1% of the sample with regard to cannabis use and in 13.2% with regard to other drug use, including heroin. It can be concluded, therefore, that the study population was characterised by high levels of severe clinical symptoms, including those associated with street drugs and alcohol abuse. While such co-existing problems of psychosis and drug or alcohol abuse are common, few of the participants in this study reported having used drug and alcohol counselling or detoxification services. This may be a reflection of the existing separation of drug and alcohol services from the community mental health services.

A very high proportion of the people with psychotic disorders have lost essential life roles and are severely impaired in daily life.

One of the most revealing results of this survey concerns the extent to which people with psychotic disorders are marginalised by the nature of their illnesses and by the societal reaction to the impairments and behaviours that result from their brain disease. At the point of the interview, that is on average some 15 years after the first onset of psychotic symptoms, the majority had lost many of the essential social roles that normally provide an individual with a sense of self-esteem and meaning in everyday life.

Social isolation is a major problem.

Impairments in daily life activities run parallel to the self-perpetuating social isolation which is a daily reality to our respondents. The vast majority (84.1%) were either single, divorced or separated, and nearly one-third were living alone. The majority (57.6%) could be described as socially withdrawn and well over one-third had no intimate relationships (including sexual ones). A very small proportion (9.3%) had a carer at home and over one-third had experienced no face-to-face contact with any close relative during the year.

Social and economic disadvantage often precedes the onset of psychosis.

A high proportion of the participants had been socially disadvantaged prior to the onset of the psychotic disorder. Thus, a large proportion (58.1%) had left school at age 16 or earlier, and 47.8% obtained no school qualification. Extremely high proportions (76.6% of the males and 43.9% of the females) never married.

Unemployment and relative poverty are widespread among people with psychotic disorders.

At the time of the survey, 72.0% were unemployed and nearly 60 per cent were unable to describe any occupation in which they were engaged in the previous 12 months. Of the 41.7% who reported some occupation, including housework or studying, almost one-half had experienced serious or moderate degree of dysfunction in the performance of such activities. At the time of the survey, the majority were living in relative poverty. As many as 85.2% were recipients of a pension or other form of welfare benefits while only 15.5% had any income from employment or other independent sources (either as their sole source of income or in addition to welfare and pension benefits).

Participants were variously accommodated in the four weeks prior to interview. Although a few had used more than one type of accommodation in this period, a large majority had used one type only. Only 14.5% had been living in their own home while 14.9% were still living in the parental home. Almost one third had been living in rented accommodation. Another 44.7% were otherwise accommodated including accommodation in institutions, hostels, group homes or other supported housing, and one-quarter of this group (11.3% of the total sample) were practically homeless or living in very marginal accommodation (living in marginal supported housing, rooming houses, hotel/rented rooms, crisis shelters, or were homeless or of no fixed address).

The special needs of people with psychoses who are homeless or marginally accommodated.

A significant number of people with psychotic disorders who live in marginal accommodation are not able to access or use the community-based mental health services. While a significant proportion of those marginalised people with psychoses have no contact with the specialist mental health services, the majority are using general hospital emergency services. This implies that the outreach and clinic-based arms of the community mental health services are not adequately addressing at present the needs of this group of people.

Poor quality of life yet satisfaction with independence.

In addition to distressing symptoms, impairments in daily life, disability in major life roles, and socio-economic disadvantage, several other variables explored in the study illustrate the poor quality of life that many people with psychotic disorders experience. Thus, 15.3% were feeling unsafe in their present locality and 17.6% reported having been a victim of violence in the previous year. One in ten had been arrested in the previous 12 months and 16.5% had attempted suicide or self-harm. Nevertheless, a high proportion (59.5%) expressed a general satisfaction with their current level of independence in the community and 43.8% were mostly satisfied with 'life as a whole' during the past year.

Some people with psychotic disorders function well.

An important finding of the study was that a sizeable minority of participants had attained a level of good social and occupational functioning and a relative stabilisation of their clinical disorders. When compared to the rest of the sample, these people were no different with regard to diagnosis and lifetime symptom characteristics such as having experienced widespread or

systematised delusions, nor were their illnesses more affective in their presentation. There were, however, several important and significant differences. The high-functioning individuals had the onset of their illnesses later in life (at age 34 years and over) and had achieved a good level of social and occupational adjustment prior to onset. Fewer of them had features suggestive of personality disorder, and significantly lower percentages had a co-morbid diagnosis of alcohol, cannabis or other substance use disorder. Female sex was significantly associated with better prognosis.

High rate of both voluntary and involuntary hospital admissions.

The majority of the participants in the survey reported a relatively high rate of utilisation of inpatient, outpatient and community treatment facilities. Thus, more than one-half of the study population had at least one hospital admission and a high proportion (45.8%) of those admitted had experienced at least one involuntary admission during the previous year. Nearly a quarter of the participants had two or more admissions during the year. The vast majority of the admissions (83.2%) were to public hospital facilities, with psychiatric units within general hospitals accounting for a considerably greater share of all admissions (53.0%) than psychiatric hospitals (36.8%). In comparison, the utilisation of the private hospital sector by patients with psychotic disorders was very low (7.5% of all admissions).

Most hospital admissions are brief but 10% of the people with psychoses spend prolonged periods in hospital.

Nearly one in three of the inpatient admissions was of brief duration (less than two weeks). However, one in ten persons with psychotic disorders had been in hospital continuously for 12 months during the year preceding the census which suggests a persisting problem of long-stay patients whose management and care needs cannot be adequately met in the community.

High utilisation of emergency services.

The data indicate a high rate of utilisation of emergency services by people with psychotic disorders. Thus, 43.9% had experienced contacts with hospital emergency departments, psychiatric emergency teams, or both, occasioned by incidents of drug overdose, self-inflicted harm, or substance abuse problems. Hospital emergency departments need to take account of the use of their services by people with psychotic disorders (including those who are marginally accommodated) and be able to respond to their needs.

Community mental health services are widely used and more than one-half of the patients with psychoses have a case manager.

By and large, the survey data suggest that community treatment and management of the psychotic disorders is well established and widely used. The majority (60.1%) of the participants reported attendances at community mental health clinics or hospital outpatient departments, and 43.1% were regular users. More than one-half (56.2%) had a case manager (a mental health worker, usually a nurse, whom the patient sees on a regular basis and who co-ordinates the care provided on a community basis). Notably, 90.0% of the participants had seen a psychiatrist or other medical officer during the year.

A high proportion of the people with psychoses are in contact with general practitioners.

The results indicate that general practitioners are a major resource in the management of people with psychotic illnesses in the community. The majority (81.3%) of the participants reported visits to general practitioners for some reason, though not necessarily a mental health problem.

The great majority find anti-psychotic medication helpful in controlling their symptoms but feel impaired by its side effects.

Anti-psychotic medication (pharmacological agents which block excess neurotransmission that may be involved in the causation or maintenance of certain symptoms of psychosis) was available to all of the respondents in this study and the majority (83.4%) felt that it was helpful in controlling the most disturbing symptoms of their psychotic illnesses. A relatively high proportion (30.8%) had been prescribed one of the newer, so-called 'atypical' anti-psychotics which are thought to cause fewer side effects. At the same time however, the majority (63.2%) described specific side effects of medication and felt impaired in their daily lives by them.

Need for improved provision of, and access to, accommodation with a flexible range of support.

A high proportion of people with psychoses who live in marginal accommodation have no access to supporting services. There is also a general lack of such supports to people with psychotic disorders living in a variety of circumstances. Given the range of disabilities described, there is a need for better access to public housing, for supports linked to accommodation of various types, and for a range of residential disability support services. There is good evidence that improved access to accommodation and support will reduce the rates of homelessness (marginal accommodation) among those living with mental illness. People with stable accommodation are more likely to be linked with specialist mental health services and to have their needs met, thus attaining a better level of functioning and improved quality of life.

There is a high level of satisfaction with the social security services but less satisfaction with housing, employment and legal aid services.

The participants in the survey pointed to a large number of governmental and non-governmental agencies providing various forms of support other than illness-related treatment and management. The services of Commonwealth Department of Social Security (now Centrelink) were those most widely used (by 68.5% of the participants) and felt to adequately meet the participants' needs (87.0% reported satisfaction with the agency). Considerably lower rates of use, and lower rates of satisfaction with respect of needs adequately met, were reported for housing, employment and legal aid. The services provided by the government departments of community services and veterans' affairs, by the family courts, local councils and ethnic services, were used by small numbers of the participants and were perceived as less satisfactory.

Non-governmental agencies are widely perceived as helpful.

Non-governmental agencies, including the churches, charitable community organisations such as the Salvation Army, St Vincent de Paul and others, and mental health self-help groups were perceived as helpful and high percentages of those who had used them felt that their needs were adequately met.

Hospital and community services.

The majority of people with psychotic disorders receive treatment and care predominantly in the community, but many also require frequent, albeit brief, hospital admissions and emergency care. The largest volume of inpatient care is provided in response to crises precipitated by acute episodes or exacerbation of symptoms, and in many instances by self-harming acts or by a co-morbid drug or alcohol abuse problem. The community-based services, such as mental health clinics, home-based and outreach services and general practitioners are actively involved in the treatment of patients with psychotic disorders and in their maintenance in the community. These services are generally available to, and accessed by, the majority of people who need them. However, while the basic needs of the patients related to assessment, case management, pharmacological treatment, and specialist referral seem to be met, the participants in the study also indicated important areas of unmet need such as the need for more information on the nature of the psychotic disorders and the existing treatment options, as well as the need for personal counselling and other psychosocial support.

Anti-psychotic medication and quality of life.

Anti-psychotic medication appears at present to be the mainstay of the treatment of people with psychotic disorders in the community. While pharmacological treatment is indeed essential in the modern management of the psychotic disorders, the high proportion of participants who attribute significant impairment in their daily lives to the side effects of medication, suggest that there is a tendency to overuse anti-psychotics for symptom control, to an extent which is not conducive to a better quality of life.

There is a serious lack of, and a need for, community-based rehabilitation programmes.

In contrast to the availability of pharmacological treatment to the vast majority of people with psychotic disorders, there is a serious lack of community-based rehabilitation services and of behavioural and psychosocial treatment and management modalities such as occupational therapy, cognitive remediation, social skills training, psychoeducation and supportive therapies. These are methods that have been shown to be effective in preventing or reducing the secondary disabilities in people with psychotic illnesses, especially when combined with judiciously monitored pharmacological treatment. Only 19.1% of the sample reported participation in any rehabilitation activities in the year preceding the interview, and an even smaller minority (6.3%) had been involved in rehabilitation programmes for 6 months or longer during the previous year. Although 72% were unemployed, only 25% were accessing community employment services. These findings highlight the need for public awareness and appropriate community responses to the problem of employment for people with psychiatric impairments. The fundamental

requirement is a change of attitude and a reduction of the discrimination experienced by these people in the labour market. The required community responses include a greater flexibility in employment policies and practices; better access to employment; vocational training; advisory and support services.

Need for a national programme of secondary prevention and disability reduction in people suffering from psychotic disorders.

The general conclusion of this study is that the so-called ‘low-prevalence’ psychotic disorders represent a major public health problem in Australia today. They are associated with a heavy burden of disease and disability and with great personal distress. The majority of the people with psychotic disorders now live in the community but only a minority attain a level of functioning and wellbeing that is commensurate with good quality of life. Many of the services available to them tend to be provided on a crisis-response basis. The need for therapeutic, housing, rehabilitative and support measures that are likely to have an impact on the course of their disorders and their social adjustment remains largely unmet. There is at present international consensus⁴⁵ that even in the absence of primary prevention and radical cure, much of the disability and distress associated with the psychotic disorders can be prevented or reduced if effective interventions and management strategies that exist today are widely available and applied consistently and systematically over the various stages of the illness. This calls for a broad programmatic approach on a national basis. Such an approach must be complex and balanced, recognising that the problem requires concerted action to impact the multiple dimensions of clinical disorders, personal functioning and socio-economic environment. The development and implementation of a national programme to reduce disability associated with psychotic illness is a feasible and timely goal for Australia. It should provide a clear focus for joint, co-ordinated efforts by mental health professionals, governmental and non-governmental agencies, and organisations of consumers and carers.

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Appendix 1

Prevalence estimates – explanatory notes

Estimation of census month prevalence rates.

Prevalences were estimated separately for screen positives and screen negatives on the basis of the proportion in each sample with an OPCRIT diagnosis of a psychosis. Estimates were made for males and females separately and, where possible, by age group. They were then summed and the ratio of estimated prevalence to the Estimated Resident Population provided the estimated prevalence rate.

For screen negatives, DIP samples were not available for all age categories. Therefore the rate of psychosis within each age group was assumed equal to that of the total.

Specific assumptions for the private psychiatrist and general practice samples.

Table 9.5 estimates assume that there were no patients with psychotic illnesses under the sole care of practitioners who did not respond to initial approaches, or who refused to participate or who claimed to have no patients with psychotic illnesses. The resulting estimates are therefore 'low'. Practitioners whose patients were screened were assumed to be a random sample of all practitioners in the catchment areas who are sole carers. It was also assumed that they were able to identify all persons with psychotic illness attending their practices during the census month with 100% sensitivity although not necessarily perfect specificity. In other words, there was some possible over-reporting (but no under-reporting) of cases by private practitioners. If the assumption were made, however, that the practitioners who did not participate cared for the same proportion of psychotic patients as those who agreed, higher rates would be obtained. This is illustrated in Table A1.1. Rates would be higher again if the participating practitioners did not screen all their patients with psychotic illness.

Table A1.1 Effects of assumptions about non-response among private practices

	Area			
	Australian Capital Territory	Queensland	Victoria	Western Australia
Private psychiatrists				
No. approached	17	41	340	67
No. responding	17	26	165	57
Ratio of 'high' to 'low' estimates	1.0	1.6	2.1	1.2
General practitioners				
No. approached	294	1078	601	242
No. responding	137	468	95	115
Ratio of 'high' to 'low' estimates	2.1	2.3	6.3	2.1

Specific assumptions for the samples of marginalised people.

All organisations providing accommodation or other services to persons who may have psychotic disorders and be unknown to mental health services were approached. As for the private service providers, it is assumed that any organisation which refused to participate was not providing sole care to persons with a psychotic disorder. Because of the small number of patients interviewed with the DIP, rates were not calculated for separate age groups. The Melbourne team systematically screened 56% of all marginal accommodation beds, although no screen negatives were interviewed. The estimates assume none of the screen negatives were psychotic. If, however, 50% of the screen negatives were psychotic, estimates for Melbourne males would be 4.3 per 1000 and for females 1.2 per 1000. In other centres coverage varied, and the number of marginalised persons interviewed was limited. The constraints involved with identifying potential cases were such that prevalence rates probably represent a lower bound of the true situation.

Specific assumptions for the samples of persons known to mainstream services but not seen in census month.

Records were searched according to the diagnosis recorded, but cases of ICD-9 code 296 were not included because of the large number of non-psychotic illnesses contained within this rubric. This implies a potential under-estimation of prevalences for this group. Among those interviewed with the DIP from the census month sample, 18% of those with an ICD-10 diagnosis of psychotic disorder would have been allocated an ICD-9 code 296.

Non-response on the DIP

Across the sites, about 50% of patients selected for the DIP failed to be interviewed which could lead to serious bias. The analyses have assumed that the rate of psychotic illness is the same among the refusals as others. In the US National Comorbidity Study⁴⁶, for example, rates of illness have been found to be higher among refusers than those accepting interview. Given the very high rate of illness among those interviewed, even among the screen negatives, it is unlikely that the estimates will have been deflated, although it is possible that the profile of types of psychotic illness could be distorted. Similarly, patients who died before interview, were too ill or could not be contacted could have had different illness profiles.

Other sources of possible bias.

- Lack of coverage during the screening phase. Following the census month, in the ACT and Victoria, a search was made of records and it was found that although up to 5% of patients had been missed by the census process, about the same number of patients were identified by the census who had not been recorded by the service providers.
- Application of the screening instrument: differences between raters, sites and between particular patients.
- Errors in the population figures, which have been assumed to be without error.
- Sensitivity and specificity of the screen and DIP.
- Inter-rater bias.
- Change in status of the patients between screening and interview.

Appendix 2

Postcodes contained within the four catchment areas

Catchment areas covered the following postcodes:

Australian Capital Territory	All postcodes except 2620 which spans both the Australian Capital Territory and New South Wales
Queensland	4025, 4068, 4073, 4074, 4075, 4076, 4077, 4101, 4102, 4103, 4104, 4105, 4106, 4107, 4108, 4109, 4110, 4112, 4113, 4114, 4115, 4116, 4117, 4118, 4119, 4120, 4121, 4122, 4123, 4124, 4125, 4127, 4128, 4129, 4130, 4131, 4132, 4133, 4150, 4151, 4152, 4153, 4154, 4155, 4156, 4157, 4158, 4159, 4160, 4161, 4163, 4164, 4165, 4169, 4170, 4171, 4172, 4173, 4174, 4178, 4179, 4183, 4203, 4205, 4206, 4207, 4208, 4211, 4256, 4270, 4271, 4272, 4275, 4280, 4285, 4287, 4300, 4301, 4303, 4304, 4305, 4306, 4307, 4309, 4310, 4311, 4312, 4313, 4340, 4341, 4342, 4343, 4346, 4540
Victoria	3002, 3054, 3065, 3066, 3067, 3068, 3078 (part), 3101, 3102, 3103, 3104, 3121, 3122, 3123, 3124, 3125 (part), 3126, 3127 (part), 3146 (part), 3147
Western Australia	6000, 6003, 6004, 6005, 6006, 6007, 6016, 6050, 6051, 6052 (part), 6057, 6058, 6076, 6100, 6101, 6102, 6103, 6104, 6105, 6106, 6107 (part), 6151, 6152

Appendix 3

Distribution of diagnoses within the study population by classification system (ICD-10, DSM-III-R)

Table A3.1 All persons: Disorder by ICD-10 diagnostic classification system (per cent)

<i>Disorder</i>	
Mild depression	0.4
Moderate depression	0.2
Moderate depression with somatic syndrome	0.2
Severe depression without psychotic symptoms	0.4
Severe depression with psychotic symptoms	3.1
Severe depress. with psychotic symptoms & mood congruent delusions	3.8
Mania without psychosis	0.2
Mania with psychosis	3.8
Bipolar disorder	7.4
Undifferentiated schizophrenia	4.2
Paranoid schizophrenia	47.9
Schizoaffective (manic)	1.0
Schizoaffective (depressed - moderate)	2.0
Schizoaffective (depressed - severe)	2.1
Schizoaffective (bipolar)	5.2
Delusional disorder	1.6
Other non-organic psychotic disorders	13.2
Did not meet criteria for psychosis	3.3
Total	100.0
Total persons	980

**Table A3.2 All persons: Disorder by DSM-III-R diagnostic classification system
(per cent)**

<i>Disorder</i>	
Major depression	1.6
Mania	0.3
Bipolar disorder	1.5
Mania with psychosis	5.2
Depression with psychosis	9.2
Bipolar with psychosis	11.7
Schizophreniform disorder	1.5
Schizophrenia	49.1
Delusional disorder	2.9
Atypical psychosis	6.0
Probable schizoaffective (manic) or mania with psychosis	1.4
Probable schizoaffective (depressed) or depression with psychosis	3.3
Probable schizoaffective (bipolar) or bipolar with psychosis	4.5
Did not meet criteria for psychosis	1.7
Total	100.0
Total persons	980