

NATIONAL SURVEY OF PSYCHOTIC ILLNESS 2010 EXECUTIVE SUMMARY AND KEY FINDINGS

The second Australian national survey of psychotic illness was conducted in 2010. The aim was to provide updated information on the lives of people with psychotic illness who receive public specialised mental health services.

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

- Two of the main symptoms are delusions and hallucinations.
- The onset for many psychotic disorders is in the late teens to early adulthood.
- Most people with psychotic illness will receive treatment, however, the stage and age at which this begins varies.

Psychotic illnesses are classified according to diagnostic criteria in the ICD-10 and include:

- Schizophrenia
- Schizoaffective disorders
- Mania with psychotic symptoms
- Bipolar affective disorder with psychotic symptoms
- Depression with psychotic symptoms
- Persistent delusional disorders
- Acute and transient psychotic disorders
- Other and unspecified non-organic psychotic disorder

The 2010 survey had four key aims to:

1. Estimate the prevalence of psychosis and age when symptoms were first experienced;
2. Describe the profile of people with psychotic illness, including their personal, social and living circumstances, and mental and physical health;
3. Determine the use of health and other services; and
4. Assess the impact of psychotic illnesses on the lives of people with these disorders and identify factors related to better outcomes.

The main focus of the 2010 survey was on consumers of public specialised mental health services administered by state/territory governments. It also included a sample of people who were only in contact with non-government organisations. It did not cover people with psychotic illness who were being treated only in the private sector or by their general practitioner.

This survey follows the first National Study of Psychotic Illness in 1997-98, which provided the first data on the prevalence of psychotic illness in the Australian population.

Public specialised mental health services and non-government organisations providing mental health services in seven catchment sites, participated in the survey. Together these sites cover 10% of the Australian population.

The sample for the survey was drawn from people receiving these services over the period from April 2009 to March 2010.

The survey methodology was based on a two-phase design:

1. All people seen by these services in the catchment sites over the period of the survey were screened, with 7,955 assessed as having psychosis and eligible for interview.
2. A random sample (1,825) of these people was interviewed over the period from April 2010 to March 2011.

The survey contained 32 modules and information was collected on over 1,500 items covering the following:

- socio-demographic characteristics, including income, education, housing, activities of daily life, employment, child and other caring responsibilities;
- family contact, social participation, crime, offending and personal safety;
- health and other services used for physical and mental health problems, covering hospital admissions, emergency department attendances, rehabilitation programs, contact with case managers, general practitioner visits and non-government organisation mental health services;
- medications used for mental health problems and their side effects; and
- physical conditions, smoking, alcohol and drug use, nutrition and exercise, as well as range of information collected through a physical examination and blood sample.

Scales were also included to determine the impact of psychotic illness on:

- overall functioning;
- quality of life;
- smoking, alcohol and drug use, and dependence;
- cognitive functioning; and
- perceived need for mental health and other support services.

ESTIMATING THE NUMBER OF PEOPLE WITH PSYCHOTIC ILLNESS TREATED BY PUBLIC SPECIALISED MENTAL HEALTH SERVICES

The 2010 national survey of psychotic illness provides information on the prevalence of psychotic disorders and the number of people receiving treatment. The prevalence is the proportion of people in the population who meet criteria for a diagnosis of these disorders at a given point in time.

Prevalence was determined for Australians with an ICD-10 psychotic illness in contact with public specialised mental health services in March 2010 and in the eleven months prior.

In March 2010, an estimated 3.1 cases per 1,000 population aged between 18 and 64 years had a psychotic illness and were in contact with public specialised mental health services.

The prevalence of psychotic disorders was higher in males than females (3.7 cases per 1,000 compared to 2.4 per 1,000) (Figure 1).

Males aged 25-34 years had the highest rates of psychotic illness (5.2 cases per 1,000).

- Almost 8,500 men in this age group were estimated to be in contact with publicly funded mental health services.
- The age groups with the next highest prevalence for males were those aged 35-44 and 45-54 years.

For females prevalence was more even across age groups at almost 3 cases per 1,000 population in those aged between 25 and 54 years.

- Young females aged 18-24 years had the lowest prevalence rates at 1.6 cases per 1,000 population.

Prevalence was also estimated for the 12-month period at 4.5 cases per 1,000 population. Scaled to the national level, this suggests that almost 64,000 people aged 18 to 64 years have a psychotic illness and are in contact with public specialised mental health services in a year.

Types of disorders

The most common psychotic disorder was schizophrenia (47.0%), accounting for the majority of males (56.3%) and one third (33.2%) of females (Figure 2).

Age of onset

Two thirds (64.8%) of people experienced their first episode before the age of 25 years.

For 32.3% of males and 38.2% of females, onset was on or after 25 years (Figure 3).

The mean age of onset was 23 years for men and 24 years for women.

For 29.1% of people the onset was gradual, taking between one and six months, and for 42.2% it took more than six months to develop.

Figure 1: One-month treated prevalence in specialised public mental health services by sex

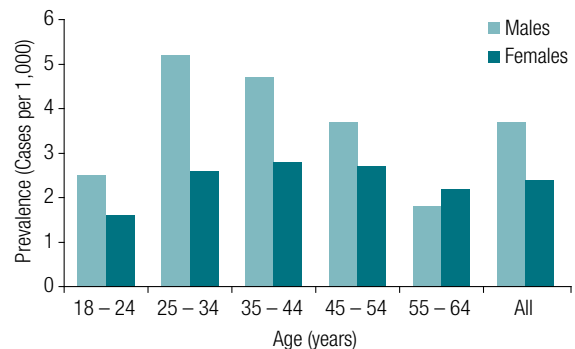


Figure 2: Diagnostic profile of ICD-10 psychotic disorders

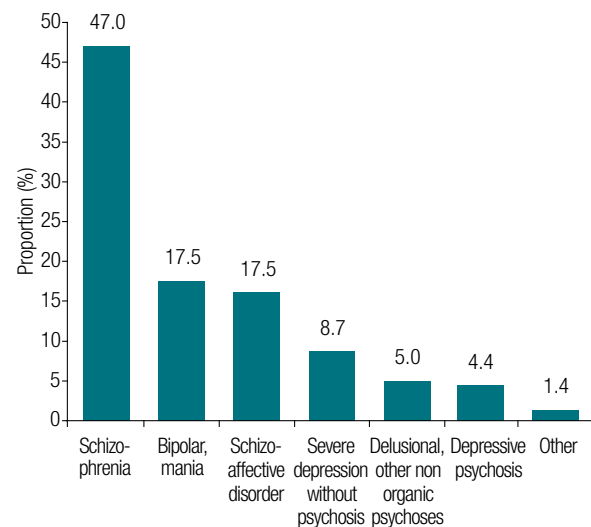
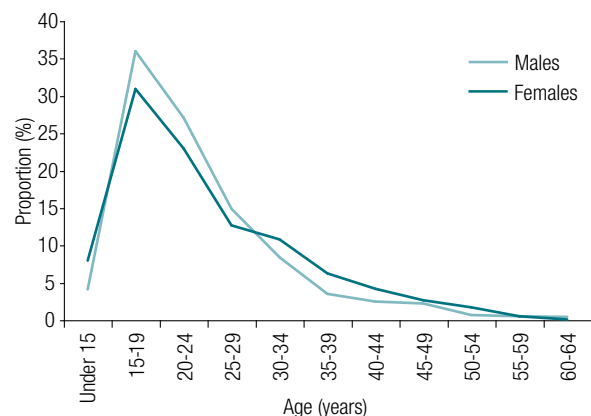


Figure 3: Age of onset by sex



DEMOGRAPHIC CHARACTERISTICS OF PEOPLE WITH PSYCHOTIC ILLNESS

Many people living with psychotic illness are in relationships, study and care for children and others just like the rest of the population. They also experience particular disadvantages that, largely due to onset of illness in late adolescence and early adulthood, impact upon their educational outcomes.

Three-fifths (59.6%) of people being treated for psychosis in the public system are male.

Almost three-fifths (57.6%) were aged 35-64 years. Just 10.6% were under 25 years (Figure 4).

Family relationships

One in ten males and one in four females with psychotic illness were currently married or in a de facto relationship.

Just over half (56.2%) of females had children of any age, with one quarter (23.6%) having dependent children living with them.

The proportion of males with children was significantly lower at 25.9% and only 5.5% had dependent children living with them.

In 14.7% of cases people were providing care to another person because of a disability, long term illness or due to old age (Table 1).

- This figure was higher for females than males, at 19.6% and 11.3% respectively.
- It was also higher for the older age group.

Education

One third (33.7%) of people with psychotic disorders had not attained a school certificate compared with 24.9% in the general population.

Almost one quarter (22.5%) had left school before Year 10.

Another third (31.5%) had completed their Year 12 qualification or leaving certificate.

About half (48.9%) of participants had completed a TAFE or trade certificate or higher post-school qualification (Figure 5).

Almost one in five (18.4%) people with a psychotic illness reported difficulty with reading and/or writing.

One-fifth (20.8%) were enrolled in formal studies in the previous year.

- Females were more likely to be studying (26.7% compared with 16.7% for males).
- The younger age group (aged 18-34 years) were twice as likely to be enrolled in formal studies (29.0% and 14.7%).

Figure 4: Age profile of people with psychotic illness treated in public specialised mental health services

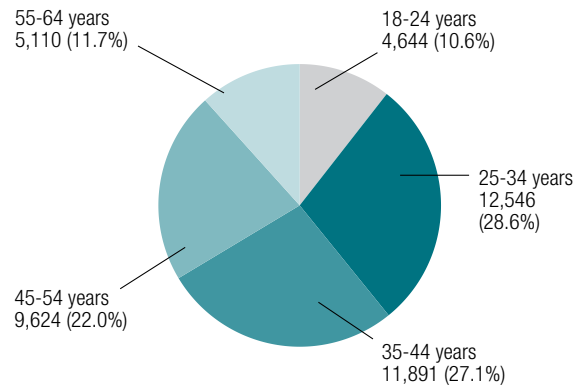
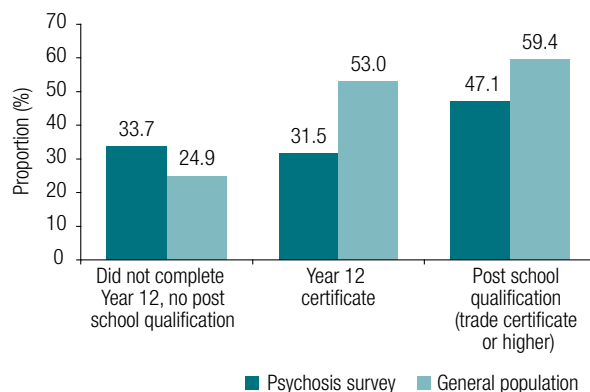


Table 1: Demographic characteristics of participants

	Proportion (%)
Males	59.6
Born in Australia	82.2
Currently married or in de facto relationship	17.1
Main source of income government pension	85.0
Dependent children living at home, including step children	12.8
Caring for another with disability, long term illness or aged	14.7

Figure 5: Educational qualification obtained



NATURE OF THE ILLNESS, SYMPTOMS AND FUNCTIONING

Psychotic illnesses can severely impact upon people’s ability to function in their daily lives.

One in twelve people (8.1%) had experienced just one episode of psychotic illness, while the majority (61.5%) had experienced multiple episodes with periods of good or partial recovery in between (29.7% and 31.8% respectively) (Figure 6).

Many people (30.5%) receiving services through the public system have continual chronic illness and one third of these experience marked deterioration over time.

The most common symptoms of psychotic illness are delusions and hallucinations (Figure 7).

- 86.7% experienced delusions in their lifetime and 41.3% currently.
- 78.9% experienced hallucinations in their lifetime and 37.5% currently.

A range of other symptoms, some of which are associated with other mental disorders, such as depression and anxiety, are also commonly experienced by people with psychotic illness.

- Depressed mood, loss of pleasure and poor concentration are frequently associated with psychotic illness, with one quarter of people currently reporting each of these symptoms (26.4%, 24.5% and 23.4% respectively).
- Over the past year, 59.8% of participants reported symptoms of anxiety and just over half (54.5%) reported one or more symptoms of depression.

Functioning

One half (51.2%) of people with psychotic illness, were assessed at interview to have been functioning well in both occupational and social domains prior to the onset of their illness.

- 70.8% of the total had been in either paid or unpaid work or studying, 68.7% had good adjustment within these roles and 63.9% reported good social functioning before the onset of first symptoms.

Most people (90.4%) reported deterioration of functioning after illness onset (Table 2).

One third (32.3%) were assessed as having a significant level of impairment in their ability to care for themselves in the previous 4 weeks and almost one-fifth (18.4%) was unable to complete a simple chore such as cleaning their room.

Two thirds (63.2%) were assessed as having a significant level of dysfunction in their capacity to socialise over the past year.

Figure 6: Course of illness

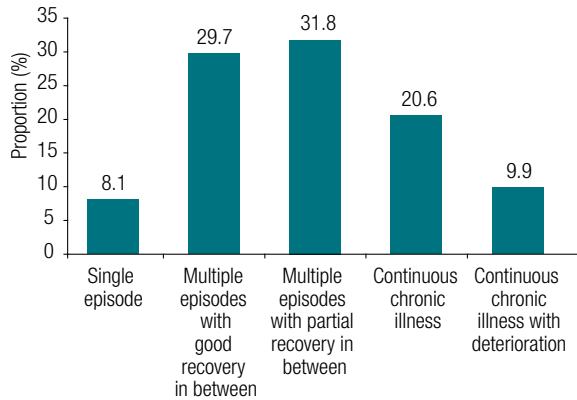


Figure 7: Current symptoms of psychotic disorders

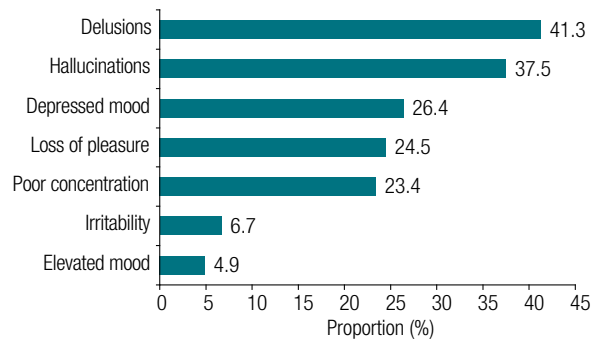


Table 2: Level of impairment

	Proportion (%)
Deterioration from pre-onset functioning	90.4
Obvious/Severe dysfunction in socialising, past year	63.2
Obvious/Severe dysfunction in self care, past 4 weeks	32.3

PHYSICAL HEALTH AND AT-RISK BEHAVIOURS

People with psychotic illness receiving public mental health services also have poorer physical health than the general population, more often experiencing chronic conditions and being more at-risk due to their high levels of obesity, smoking, and alcohol and drug use. They are far more likely to harm themselves. They also think about and attempt suicide at rates far higher than the general population.

Physical conditions

Chronic back, neck or other pain were common (31.8%) amongst people with psychotic illness, followed closely by above average asthma rates (30.1% compared to 20.2% for the general population) and heart or circulatory conditions (26.8% compared to 16.3% for the general population) (Figure 8).

One quarter (24.0%) of people with psychosis were at high risk of cardiovascular disease.

Almost half (45.1%) of people with psychotic illness were obese (Figure 9).

Physical activity levels were far lower in people with psychosis, with 96.4% classified as either sedentary or undertaking low levels of exercise in the previous week compared to 72.0% for the general population.

Smoking, alcohol and drug use

Two thirds (66.1%) of people with psychosis smoke, smoking on average 21 cigarettes per day (Figure 10).

- Almost one third (31.0%) of people had made an effort to quit in the last year, but just over one quarter (27.3%) had never tried.

Alcohol abuse was high, with 58.3% of males and 38.9% of females assessed by interviewers as consuming alcohol at levels that constitute abuse or dependence at some point in their lifetime (Figure 10).

- This compares to 35.3% of males and 14.1% of females in the general population.

Rates of lifetime use of cannabis or other illicit drugs were very high, with 63.2% of males and 41.7% of females assessed by interviewers as using at levels that constitute abuse or dependence (Figure 10).

- This compares to 12.0% of males and 5.8% of females in the general population.

Only 12.9% of people with psychotic illness were participating in drug and alcohol treatment programs.

Suicidality

Just over one-tenth (11.5%) of people reported that they were thinking about suicide at the time of interview and two thirds (67.0%) had done so in their lifetime.

Half (49.5%) reported they had attempted suicide at some point in their lifetime.

- This compares to only 3.7% in the general population.
- Females were more likely to have attempted suicide than males (57.5% and 44.2% respectively).

Figure 8: Chronic conditions

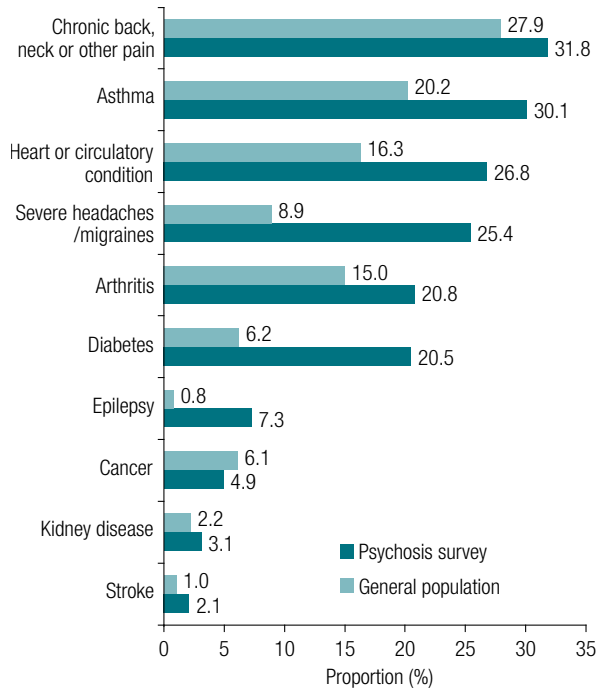


Figure 9: Overweight and obesity

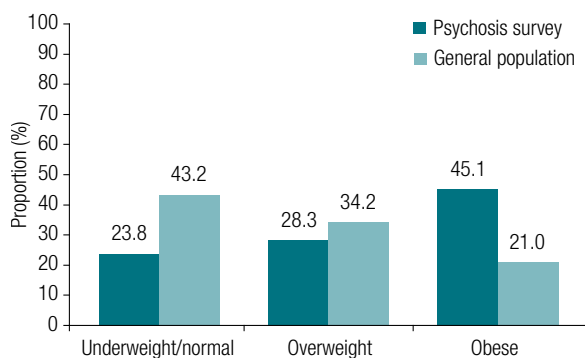
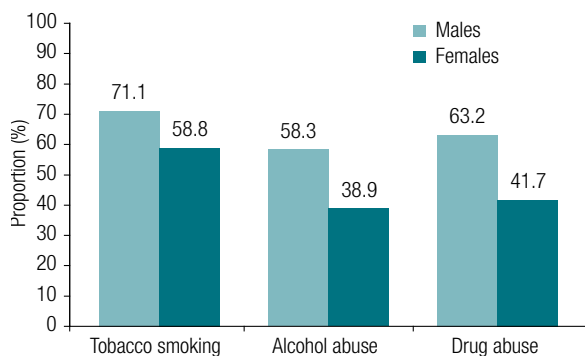


Figure 10: Smoking, and alcohol and drug abuse



SERVICE AND MEDICATION USE

Mental health care in Australia is provided through hospital-based and public specialised mental health services managed by states and territories, private sector services delivered by general practitioners, psychiatrists and psychologists and non-government organisations.

Service utilisation

The majority of people with psychotic illness used a wide variety of health services both for their mental and physical health problems (Figure 11). Almost all (95.3%) had used services for their mental health problems and 81.0% had used services for their physical health problems.

- Most people (88.2%) had visited a general practitioner in the past year.
- Most (86.3%) had used outpatient or community clinics and ambulatory health care services in the past year.
- Two-fifths (41.0%) presented to an emergency department and one quarter (26.4%) had done so for a psychiatric problem. In addition, 17.2% had telephone contact and 16.3% had face-to-face contact with a psychiatric emergency service.
- One in five people (20.7%) had at least one involuntary inpatient admission and one-fifth (19.2%) were under a community treatment order in the past year.

One third (34.8%) of people with psychotic illness had one or more psychiatric inpatient admissions in the past year, with an average of 40 days in hospital (Figure 12).

- Two-fifths (43.0%) spent from four to thirteen weeks in psychiatric inpatient treatment.

Medication use

Most (91.6%) people were taking prescribed medications in the previous four weeks, with four-fifths (81.6%) taking antipsychotics.

- The majority of people were on atypical psychotics (74.0%) (Figure 13).

Newer ‘atypicals’ better control delusions and hallucinations, however, they do not alleviate other symptoms for which people may receive a variety of medications.

- 37.4% were on antidepressants.
- 26.7% were on mood stabilisers.

Medication side effects were common, with 44.7% experiencing drowsiness, 39.5% dry or watery mouths and 37.5% weight gain.

- People reported that the impact of the side effects on their daily lives was moderate or severe for 29.9%.

Two-fifths (41.1%) were also using medications for physical health conditions. The most common medications were cardiovascular (18.2%), followed by endocrine (14.7%).

Figure 11: Service use in the past year

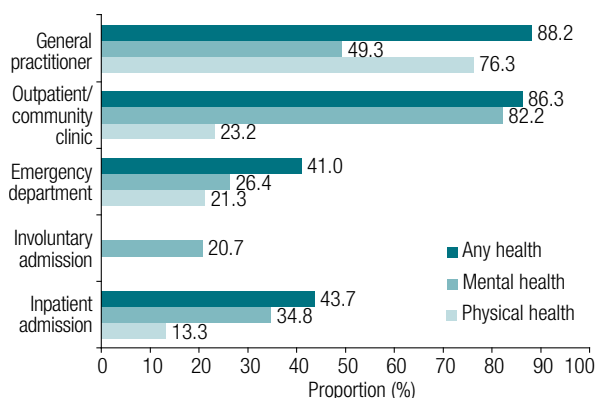


Figure 12: Psychiatric inpatient treatment in the past year

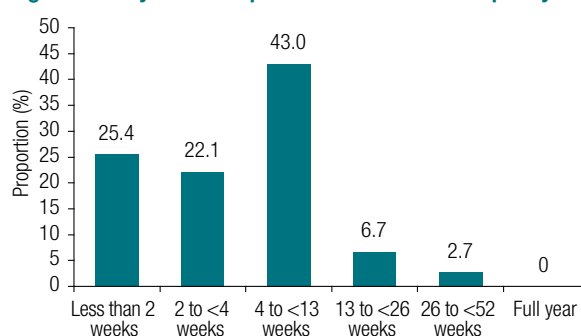
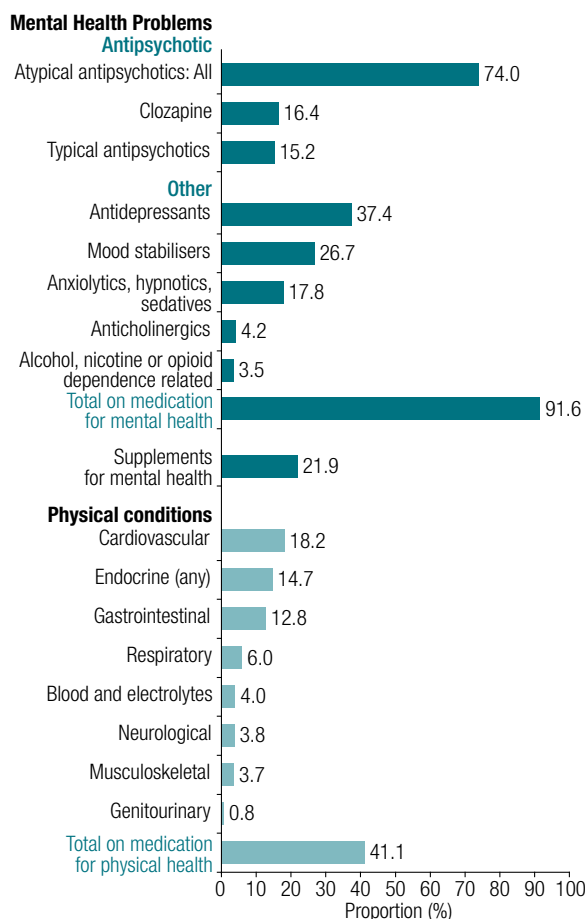


Figure 13: Medication use in the past year



NON-GOVERNMENT SERVICES AND CASE MANAGEMENT

Non-government organisations are a key component of the mental health care system, being publicly funded to provide a variety of mental health programs and support services to people with mental illness.

Non-government organisations

Three in ten (29.8%) people with psychotic illness received mental health services through non-government organisations in the past year.

Almost one quarter (22.4%) of people had attended a group rehabilitation program run by a non-government organisation and 90.0% found these programs somewhat or very helpful.

Non-government organisations also provide one-on-one support (Figure 14).

- Two thirds (68.6%) of people received counselling or emotional support.
- Information on recovery planning was provided to 41.4% of people.
- Many were helped to access other community services (45.4%) or link with other mental health services (36.6%).

An estimated 0.4 cases per 1,000 population aged 18-64 years or 6,200 people with psychotic illness were solely using mental health services provided by non-government organisations in March 2010. Many will have received mental health services in the preceding 11 months.

Three quarters (74.3%) were older, aged 35-64 years (Figure 15). At interview, they were found to be less likely than public specialised mental health service users to report inpatient (32.7% versus 45.6%) or involuntary admissions (7.8% versus 22.7%), or have attended an emergency department (31.7% versus 43.0%) or outpatient clinic (65.9% versus 92.8%) in the past year.

Case managers

More than two thirds (69.2%) of people with psychotic illness had a case manager in the past year, with 61.6% provided by public services and 20.2% through non-government organisations.

Around two thirds of people were very satisfied with their case manager (Table 3).

Three quarters were satisfied with the frequency of contact (76.5% for public service and 77.8% for non-government provided case managers).

Personal Helpers and Mentors Services

Personal helpers supported 12.3% of people, assisting 64.0% to manage daily activities and almost half (49.3%) of their clients with referrals to services, and by accompanying them to appointments and by acting as an advocate (both 45.3%).

Figure 14: Use of non-government organisation one-on-one support programs in past year

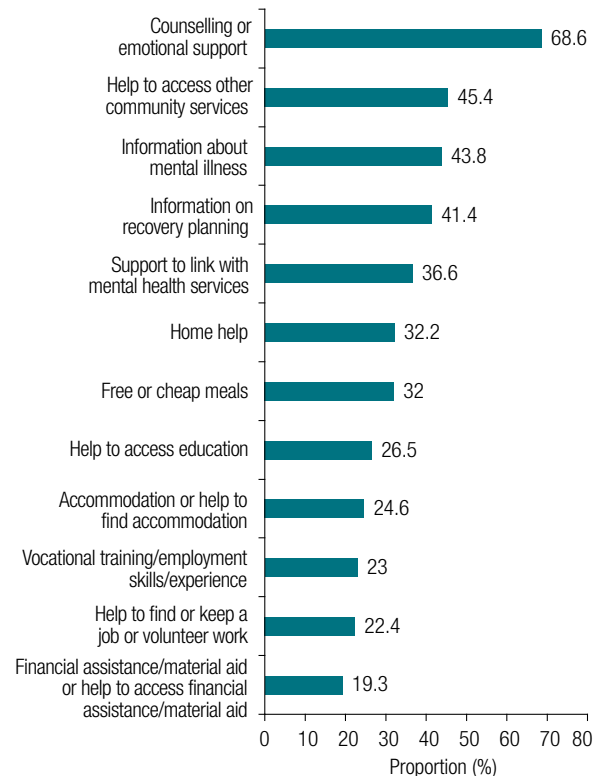


Figure 15: One-month treated prevalence for people solely in contact with non-government organisations

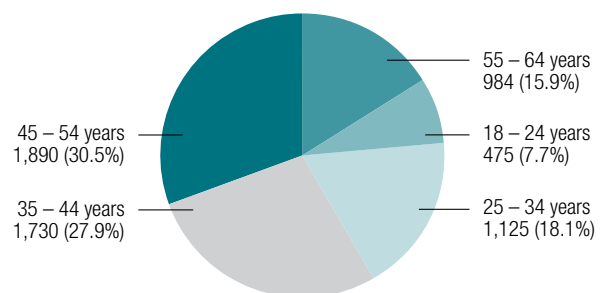


Table 3: Case manager contact and satisfaction by sector

Proportion of people (%)	Public services	Non-government services
Contact as often as preferred	76.5	77.8
Frequency of contact		
Once every 1-4 weeks	54.4	30.4
Once a week or more	28.1	64.0
Satisfaction with case manager		
Very satisfied	62.2	69.6
Somewhat satisfied	22.8	19.8

GENERAL PRACTITIONER SERVICES

General practitioners play a key role in providing health care to people living with psychotic illness, not only treating their physical conditions, but also in providing mental health services.

The majority of people with psychotic illness (88.2%) visited a general practitioner in the past year, which is slightly higher than access by the general population (79.3%).

Half (49.3%) saw their general practitioner for a mental health related visit, whilst 76.3% had a general physical health visit.

- One in ten (9.4%) had a general practitioner mental health care plan.
- People with psychotic illness visited a general practitioner on average 9 times in the past year and one quarter (28.8%) averaged over 12 visits in the past year. This compares to a general population average of 5 visits a year.

Further information was obtained from the general practitioner of survey participants.

- The majority (83.2%) saw the same general practitioner at each visit.
- Two thirds of people (65.4%) averaged 10-19 minute consultations (Figure 16).
- Only 1.2% had longer consultations of 40 minutes or more.
- The most common reason for a general practitioner visit was for a new prescription (68.8%) or a blood test (52.8%) (Figure 17).
- In terms of mental health related visits, 42.0% had attended to have psychotic symptoms reviewed, almost one third (31.3%) had attended for depression and one third (30.3%) for anxiety.
- Most (86.5%) treated their patient in collaboration with a mental health team.
- In the past 12 months, general practitioners had treated one third of participants (32.2%) for metabolic, cardiovascular or kidney disorders and had referred 11.4% for further specialist treatment.

When asked the top three difficulties in treatment of people with psychotic illness, general practitioners noted treatment non-adherence (22.1%) at the top of their difficulties, however, 44.3% noted no difficulties in treating people with psychotic illness.

When asked to name the top three challenges faced by people living with psychotic illness, 41.3% of general practitioners listed social isolation, 37.7% lack of employment and 37.5% financial problems (Figure 18).

Figure 16: Consultation length in minutes

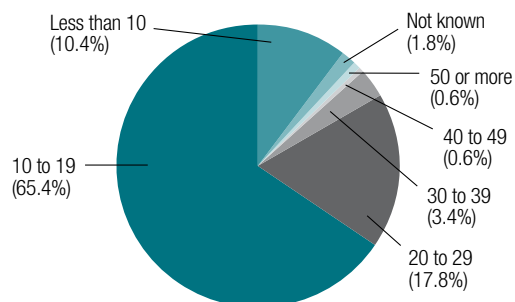


Figure 17: Reason for consultation with general practitioner

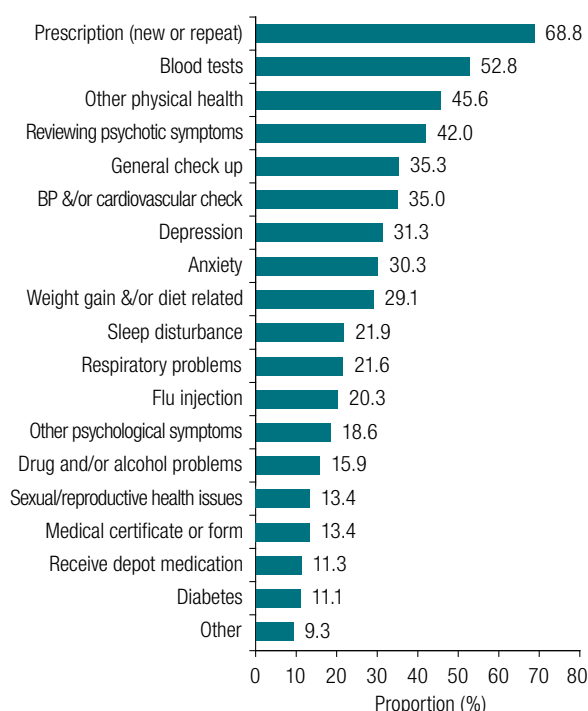
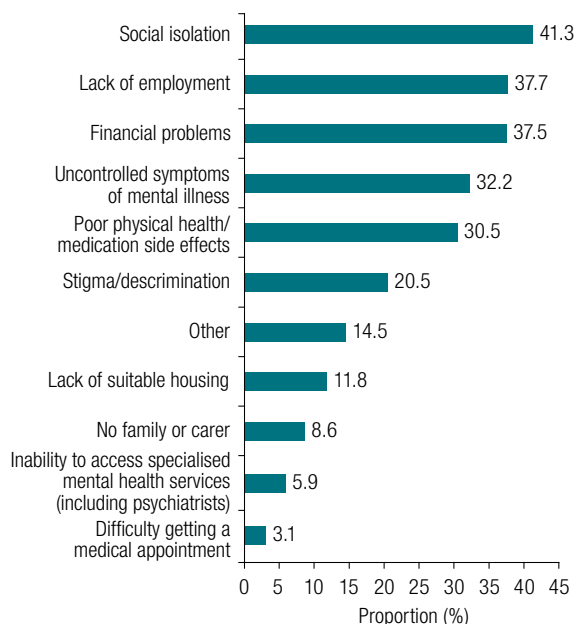


Figure 18: Top three challenges for people with psychotic illness identified by their general practitioner



EMPLOYMENT AND HOUSING

People with psychotic illness experience very high rates of unemployment and low rates of labour force participation. They are also at greater risk of homelessness. Factors contributing to these high rates include social isolation, family breakdown, stigma, discrimination and the need for acute care, including hospital admissions.

Income and employment

Government pensions were the main source of income for 85.0% of people.

One third (32.7%) were in paid employment and 30.5% were employed on a full-time basis (Figure 19).

- 74.8% were in open, competitive employment;
- 7.6% were self-employed; and
- 17.1% were in sheltered, non-competitive employment.

Hours worked varied by sex and age:

- Males worked more hours per week in paid employment than females (26 compared to 20 hours respectively).
- Younger people (18-34 years) worked 25 hours on average compared with 22 hours per week for those aged 35-64 years.

Half (48.5%) of males were employed as labourers, a further 14.2% as technicians/trade workers and 12.1% as community/personal service workers.

For females, the most common occupations were labouring (26.5%) and community/personal service work (26.4%).

Just over half (56.2%) of those in paid work had disclosed their mental health status to their employer.

Housing and homelessness

Half (48.6%) of people were renting, with 26.8% in public rentals and 21.8% in private rentals (Figure 21).

Whilst half (51.5%) were satisfied with their current living situation, 12.5% were somewhat or very dissatisfied.

Two-fifths (39.8%) would prefer to live in their own home or unit.

One-tenth (10.4%) of people had changed accommodation more than once in the previous year (Figure 22).

Some 5.2% of people were homeless at the time of the study and 12.8% had experienced periods of homelessness over the previous year.

Half (52.8%) had discussed accommodation needs prior to hospital discharge, but 6.9% reported they had not been given any assistance and were homeless on discharge.

Figure 19: Source of income

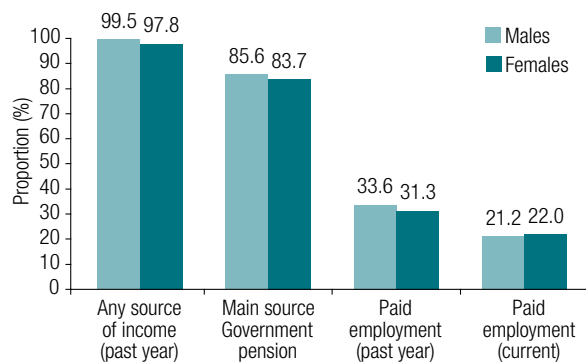


Figure 20: Employment type for those employed in past year

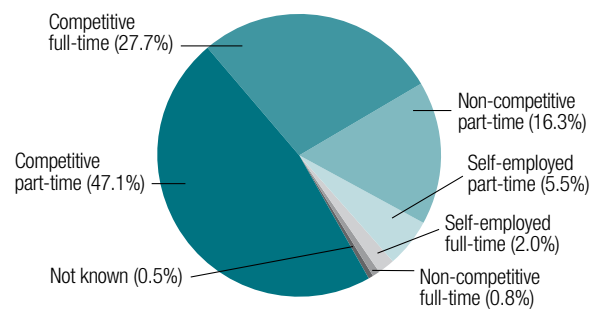


Figure 21: Current and preferred accommodation

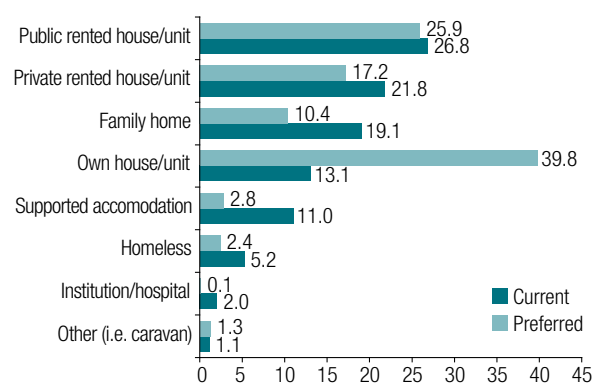
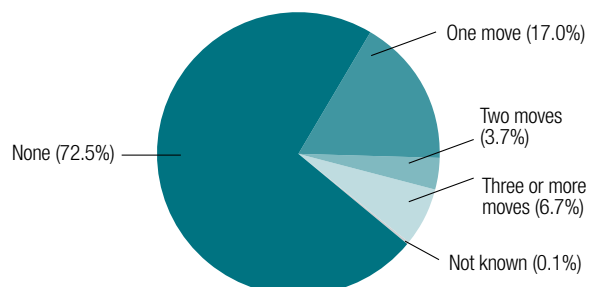


Figure 22: Housing changes in past year



ISOLATION, SOCIAL SUPPORT AND SATISFACTION WITH LIFE

People with psychotic illness are often isolated by the symptoms of their illness and this isolation can be exacerbated by multiple episodes of illness, periods of hospitalisation and stigma and discrimination that make maintenance of family and social contacts more difficult.

Over half (57.2%) of people with a psychotic illness reported experiencing a distressing or traumatic event in childhood, with 16.1% reporting being sexually abused.

Nearly one quarter (22.4%) of people reported feeling socially isolated and lonely.

- Two thirds (69.3%) said their illness made it difficult to maintain close relationships.

Almost one third (31.0%) of people reported they lived alone, however, 40.6% of reported they would prefer to be living with someone else.

Most people (96.1%) had some contact with a family member over the last year. For many (65.4%) this was daily and another 18.2% had weekly contact (Figure 23).

The majority of people had at least one friend (86.5%), however, 13.3% had no friends at all, 14.1% had no one they could rely on and 15.4% had never had a confiding relationship.

Two thirds (68.6%) had not attended any social programs and a similar proportion (69.4%) had not attended any recreational activities.

Support, needs and satisfaction

Just over half (56.4%) of people with psychotic illness reported receiving no or minimal support from any source.

One quarter (24.5%) of people had a carer. For 40.8% of these people, this was their mother, for 25.7% it was a partner and for 5.4% it was their child.

Half (50.6%) received some help with domestic responsibilities. Almost all (94.5%) who received this assistance found it to be very or somewhat helpful, with 35.1% noting it would be difficult to maintain their responsibilities without this help.

About half (55.5%) identified unmet needs in relation to their treatment. Almost one third (30.5%) reported the need for assistance in other areas of their lives including, but not limited to, housing, finances, employment, legal assistance and practical assistance.

Seven out of ten (71.9%) people were satisfied with their independence in the past four weeks.

Financial matters, social isolation and lack of employment were noted as the biggest challenges over the next 12 months (Figure 24). These were the same top three challenges noted by general practitioners they visited.

In spite of the difficulties facing them, 77.4% of people believed their circumstances would improve over the coming year.

Figure 23: Contact with others and formal social events

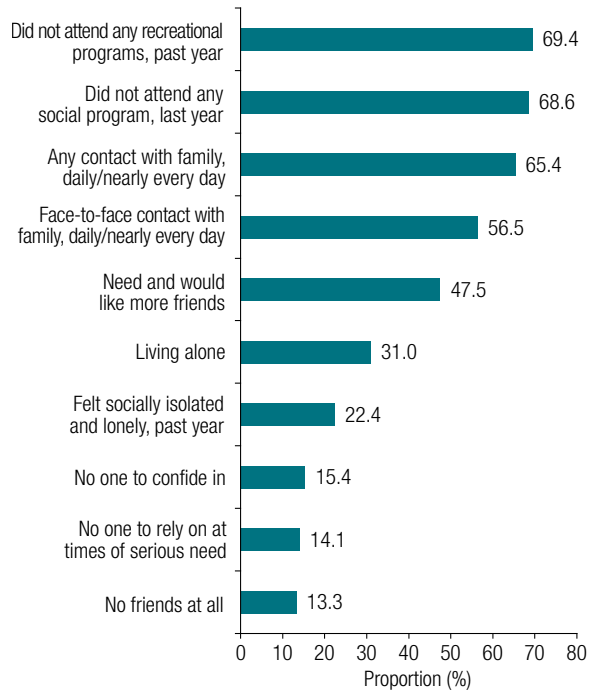
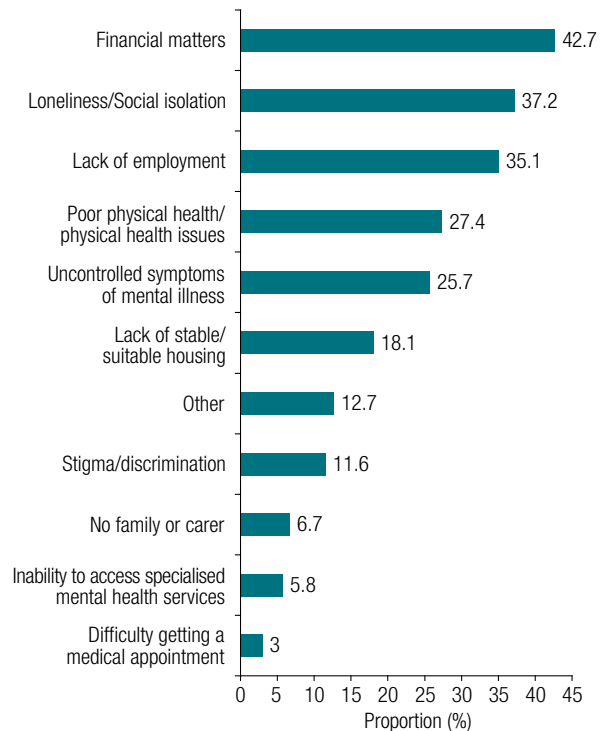


Figure 24: Challenges over the next year



HOW THINGS HAVE CHANGED SINCE 1997-98

Since 1997-98 when the first national survey of psychotic illness was conducted, there have been major changes in mental health service delivery particularly affecting public specialised mental health services, which are key providers of services to people with psychotic illnesses. Both the 2010 and 1997-98 surveys collected information from people receiving these services in a census month and comparison of these data provides insights into the impact of these changes.

The one-month prevalence of psychotic illness in people receiving public mental health services in 2010 was 3.1 cases per 1,000 population. This is consistent with that found in 1997-98, which was estimated as 3.6 cases per 1,000 population.

There appear to be some changes in the course of disorder people experience (Figure 25).

- The majority of people had multiple episodes of psychotic illness, but more people experienced periods of good recovery in between these (29.3% compared with 21.3% in 1997-98).
- The proportion of people experiencing deterioration due to chronic psychotic illness had halved since 1997-98 (11.3% compared to 23.6%).

Changes in service use are consistent with changes in mental health service delivery.

- Hospital admissions for mental health reasons decreased by 35.9%.
- Involuntary admissions decreased by a third from 31.4% to 22.7%.
- There was a 60.7% increase in the use of community rehabilitation or day programs.
- One quarter (26.5%) of people received mental health services from non-government organisations compared with 18.9% in 1997-98.
- The proportion of people with a psychotic illness who had a case manager increased from 71.9% to 78.1%.
- General practitioners continue to be major providers of services, with the proportion visiting general practitioners increasing from 76.7% to 87.8%.

By 2010, 78.4% of people were taking atypical antipsychotics compared with 37.1% in 1997-98.

More people were in their own home or rented accommodation (68.4% compared with 49.0% in 1997-98) and the proportion in supported accommodation had doubled to 10.9%.

The proportion of people who had been homeless at some time in the previous 12 months more than halved (5.0% compared with 13.0% in 1997-98).

Smoking rates remained very high and lifetime alcohol and drug abuse or dependence increased markedly, both rising from around 30% to just over half having these disorders (Figure 27).

Figure 25: Course of disorder, 1997-98 and 2010

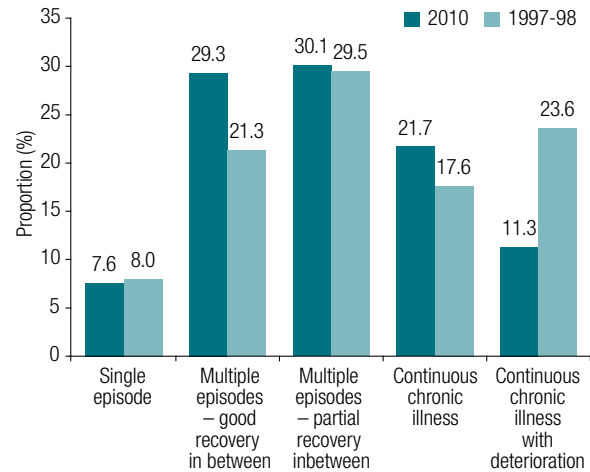


Figure 26: Health service use, 1997-98 and 2010

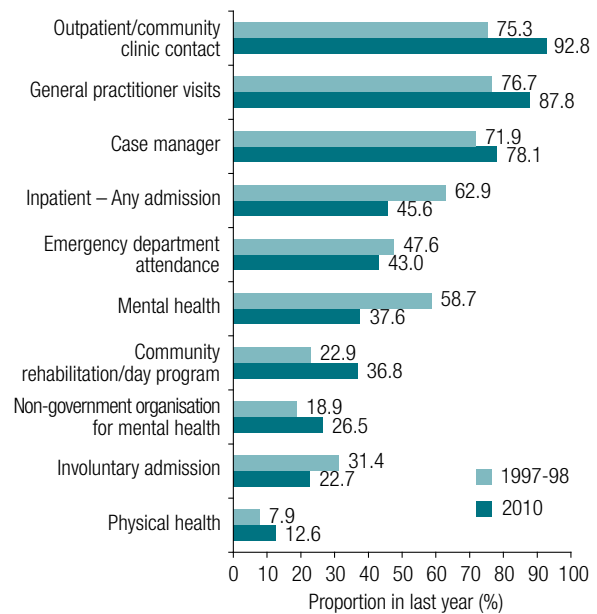


Figure 27: Smoking, and alcohol and drug abuse or dependence, 1997-98 and 2010

