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Report based on the analysis of the ONS Survey of Psychiatric Morbidity among Adults in Great Britain carried out in 2000 for the Department of Health, the Scottish Executive Health Department and the National Assembly for Wales

Adults with a psychotic disorder living in private households, 2000

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1 Tables showing percentages

The row or column percentages may add to 99% or 101% because of rounding.

The varying positions of the percentage signs and bases in the tables denote the presentation of different types of information. Where there is a percentage sign at the head of a column and the base at the foot, the whole distribution is presented and the individual percentages add to between 99% and 101%. Where there is no percentage sign in the table and a note above the figures, the figures refer to the proportion of people who had the attribute being discussed, and the complementary proportion, to add to 100%, is not shown in the table.

The following conventions have been used within tables:

- \- no cases
- 0 values less than 0.5%
- .. data not available

A percentage may be quoted in the text for a single category that is identifiable in the tables only by summing two or more component percentages. In order to avoid rounding errors, the percentage has been recalculated for the single category and therefore may differ by one percentage point from the sum of the percentages derived from the tables.

2 Statistical significance

Because of the low prevalence of psychotic disorders and the severity and nature of these conditions, it is difficult to obtain a sufficiently large and fully representative sample of people with psychotic disorder from the general population for detailed analysis. Therefore, the percentages presented in this report are indicators of prevalence only within this particular sample, and should not be taken as estimates for the total population of people with a psychotic disorder. However, the sample is likely to be typical of many of the people with psychotic disorders within the household population and to represent people across the range of severity of disorder. Differences in service use and other circumstances have been investigated by means of multi-variate analysis. Where an association is said to be statistically significant this refers to comparisons within this sample group only and does not indicate that the same association would be found to be significant within the whole population of people with psychotic disorder.

3 Small bases

Very small bases have been avoided wherever possible because of the relatively high sampling errors that attach to small numbers. In general, percentage distributions are shown if the base is 30 or more. Where the base is lower, actual numbers are shown in square brackets.

Authors' Acknowledgements

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Dr D Jones, Department of Health
Ms T Jones, National Assembly for Wales
Dr J Loudon, Scottish Executive
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Summary of key findings

Background, aims and method (Chapter 1)

- The data covered in this report come from two sources: a survey which was carried out in 2000 and is a repeat of an earlier survey of adults living in private households, and a supplementary sample of people with psychosis identified through GP records held on the General Practice Research Database.
- The analysis is based on information obtained from 60 people identified as probably having a psychotic disorder in the 2000 survey of adults living in private households and 140 people identified from GP records as having at some time been given a diagnosis of psychotic illness or prescribed medication for treating such conditions.
- The aim of the report is to investigate the circumstances of adults with a psychotic disorder, and to identify characteristics associated with their functioning, circumstances and use of services.
- The severity, nature and comparative rarity of psychotic illness makes it difficult to obtain a representative sample of people with psychotic disorder living in the community of sufficient size for detailed analysis. Therefore, the results presented in this report and tests for the significance of associations relate only to this particular sample and may not be true for the total population of people with a psychotic disorder. However, the sample is likely to be typical of many of the people with psychotic disorders within the household population and to represent people with a range of severity of disorder.

Medication and service use (Chapter 2)

- Overall, 91% of this sample of people with a psychotic illness were receiving some form of treatment, either medication or some form of counselling or therapy.
- Just over four-fifths (82%) of respondents were receiving one or more psychoactive medications. The majority of these, 63% of the sample as a whole, were taking drugs used in the treatment of psychoses, over a third of the sample (37%) were taking antidepressant medication, and just over a fifth (22%) were taking hypnotics or anxiolytics.
- In this sample, 10% of people who were using antipsychotic medication were receiving them as depot injections (injections administered at regular intervals, for example weekly or monthly). This is substantially fewer than was found in the sample from a similar survey in 1993, when a quarter of the sample living in private households were receiving antipsychotic depot injections.
- Although similar proportions of people aged under 45 and 45 and over were receiving medication, younger respondents were more likely to be receiving psychological therapy or counselling. Over a third (39%) of those aged under 45 were receiving counselling or therapy, either alone or with medication, compared with just over a fifth (22%) of those aged 45 and over.

- The most common group of non-medicinal therapy reported was psychotherapy and psychoanalysis – reported by almost half (49%) of those receiving counselling or therapy, while over two-fifths (42%) were receiving counselling, and 14% were being treated through behavioural or cognitive therapy.

- In the year before the interview, three-fifths (62%) of respondents had consulted their general practitioner about a mental or emotional problem and 10% had done so in the previous two weeks. Younger people and those with higher levels of neurotic symptoms were more likely to have spoken to their GP in the previous 12 months.

- Overall, 3% of the sample reported an in-patient stay in the last quarter relating to a mental health problem and over a fifth of the sample (22%) reported one or more out-patient visits. Younger respondents were almost twice as likely as those aged 45 and over to have attended an out-patient department in the three months before interview in connection with a mental health problem (30% compared with 17%).

- Two-fifths (40%) of the adults in this sample of people with a psychotic disorder had had contact with community care services during the previous quarter. People living alone and those who were economically inactive had increased odds of receiving such services.

- More than a quarter (27%) of informants had used one or more day activity services (such as a community mental health centre, day activity centre or sheltered workshop) in the previous year, and 20% in the three months before interview. Men were twice as likely as women to have used a day activity service in the past year: 38% had done so, compared with 17% of women. People living alone, in particular, and those in manual social classes were more likely to have used these services once other factors were taken into account.

Activities of daily living (Chapter 3)

- Over half of this sample of people with psychotic disorder (56%) reported difficulties with one or more activities of daily living (ADL). Most of these (49% of the whole sample) said that they needed help to overcome at least one of these difficulties.

- People were most likely to have difficulty with practical activities (35%), dealing with paperwork (32%) and household activities (26%) and least likely to report having difficulty with medical care (7%) or personal care (12%).

- Respondents with high levels of neurotic symptoms (those with CIS-R scores of twelve or more) had significantly increased odds of having difficulties with all aspects of ADL, except for practical activities.

- Those who were economically inactive also had increased odds of having difficulties with using transport, managing money, household activities and practical activities, but not personal care, medical care or dealing with paperwork.

- People who reported having a long-standing physical complaint had greater odds of reporting difficulties with personal care and practical activities only.

- Not surprisingly, the level of educational qualifications obtained was inversely associated with the need for help with paperwork – people with qualifications at A level or above had lower odds of having difficulties dealing with paperwork than those with lower levels of qualifications.

- The majority of those who needed help with one or more activities were receiving help with at least one ADL for which help was needed. However, of those who needed help, 4% received none for any ADL for which they needed it and 11% had at least one difficulty for which they had an unmet need for help.

- Family and friends were the most common providers of help for activities of daily living. Forty-one per cent of those needing help received it from their spouse or partner, 36% from another relative, and in 32% of cases from a friend. Health or social care workers provided help for 19% of informants who needed help, while nearly a quarter of those needing help (23%) received help from others including, for example, paid domestic help and solicitors.

Economic activity and finances (Chapter 4)

- In this sample of people with a psychotic disorder, a very high proportion of people, 70%, were economically inactive. Just over a quarter (27%) were in paid employment, half of them full time and half part time.

- The majority (62%) of those who were economically inactive were not seeking work because they were long-term sick or disabled, another fifth (20%) were retired and 12% were looking after their family or home.

- Four variables were found to be independently associated with being unable to work due to long term illness or disability. The strongest association was with CIS-R score: having a high CIS-R score more than quadrupled the odds of not being able to work due to illness or disability. Living in rented accommodation trebled the odds, while being male and living alone also both independently increased the odds.

- Among the adults in our sample who were in paid employment at the time of interview, almost half (47%) said that they had taken time off in the past year because of their health or the way they were feeling.

- Among those who were not currently working but had previously had a job, the majority, 59%, said they were not working because the way they had been feeling made it impossible for them to do any kind of job. Eighteen per cent were not working because of a physical health problem, 5% had been unable to find a suitable job and 12% said they did not want or need a job.

- Overall, at the time of interview, 79% of respondents were receiving some form of state benefit or allowance. Twenty-eight per cent of informants were in receipt of income support, family credit or working families tax credit. Over a half of informants, 52%, were in receipt of a benefit relating to a disability.

- Apart from benefits, over half of the sample (54%) had no other sources of income, and three respondents (2%) said they had neither state benefits nor other sources of income. Nearly a quarter (24%) of respondents had some earned income, including 8% of those who received benefits. Overall 14% had a pension from a former employer.

- Almost half of this sample (45%) had a gross weekly income of under £100. For those on state benefits and without other sources of income, this rose to 61%, compared with 29% for those in receipt of state benefits but who had other sources of income, and 21% of those with other income and no state benefits.

- Overall, 17% of respondents reported that, in the past 12 months, there had been times when they had been seriously behind in paying bills. Almost a tenth (9%) of the sample had been disconnected from one or more of the utilities (water, gas, electricity, telephone) in the previous twelve months.

Social networks and perceived social support (Chapter 5)

- Among this sample of people with a psychotic illness, a fifth (20%) reported feeling close to fewer than four people. In comparison, in the survey of adults living in private households in 2000 only 5% had a small primary support group (less than four people).

- Just over one fifth (21%) of this sample of people with psychotic illnesses were classified as having a severe lack of perceived social support, while 25% had a moderate lack and 54% had no lack of social support.

- Sex and age were both associated with having a severe lack of social support. Twenty-eight per cent of men, compared with 15% of women, were classified as having a severe lack of social support, as were 31% of people aged under 45 compared with 14% of those aged 45 and over.

Tobacco, alcohol and drugs (Chapter 6)

- A large proportion of this sample of people with a psychotic illness were, or had been, smokers: 44% were smokers, a fifth (20%) were ex-smokers and just over a third (36%) had never been a regular smoker. The 2000 General Household Survey found that, amongst the general adult population aged 16 to 74 years, 29% smoked, 22% were ex-smokers and half (50%) had never smoked.

- As well as having a high prevalence of smoking, a large proportion of people in the sample reported smoking heavily (20 or more cigarettes a day). Just over a quarter (27%) of the sample of people with psychotic illness were heavy smokers while only one in twelve (9%) of the general population in the same age group did so.

- Age group and tenure were independently associated with both smoking and heavy smoking in this sample of people with a psychotic disorder. Younger people and those who rented their homes had greater odds of both smoking and being a heavy smoker. High levels of neurotic symptoms were also associated with greater odds of being a heavy smoker.

- Among this sample, 27% of respondents had an AUDIT score of 8 or more – that is, they were found to have a hazardous level of drinking in the year before interview – including 14% who were classified as alcohol dependent. In the survey of adults living in private households in 2000 25% of people were assessed as having hazardous drinking patterns.

- Men were more likely than women in this sample to have a hazardous pattern of alcohol consumption, and younger people were more likely than older people to do so. This is similar to the pattern seen in the general population.

- Overall, 30% reported ever using one or more illicit drugs, and 8% reported having done so within the last twelve months. These figures are similar to the rates found in the household survey.

Stressful life events, suicidal thoughts and behaviours (Chapter 7)

- Over two-thirds (70%) of this sample of people with a psychotic illness had thought about suicide at some time in their lives and 45% had attempted suicide. In addition, 21% had harmed themselves without intending to commit suicide. These rates are far higher than those found in the general household population in which the corresponding figures are 13% reporting suicidal thoughts, 4% attempted suicide and 2% deliberate self-harm at sometime in their lives.

- Almost everyone in the sample (97%) had experienced one of the stressful life events in the group concerning relationship problems, illness and bereavement. Compared with the general household population, this sample reported experiencing particularly high rates of serious illness or assault to themselves, 63% compared with 26% in the general population, and divorce or separation, 47% compared with 22%. They were also more than twice as likely to report a serious problem with a close friend or relative, 30% did so.

- Stressful events relating to employment and finances were also far more common in this sample than in the general household population. They were also much more likely to report having had a problem with the police involving a court appearance – 22% reported having done so. Men in the sample were more likely than women to report almost all of this group of stressful events.

- A very high proportion of people in this sample reported experiencing one of the types of victimisation covered in the survey. Over a fifth (21%) reported sexual abuse and the rate was markedly higher among women and younger people (31% in each case). About a quarter of the sample said they had experienced violence in the home (25%) and being homeless (23%), while 41% said they had suffered bullying.

- Over half of the sample, 57%, had experienced six or more stressful life events and 17% reported ten or more of them.

- The proportion of people in this sample who reported suicidal thoughts and, in particular, self-harm with or without suicidal intent, increased with the number of stressful life events they reported. Those who reported eight or more events had particularly high rates: over 80% reporting suicidal thoughts and over 60% attempting suicide at some time in their lives.

- Among those who reported a serious problem with a close friend or relative, 66% said they had attempted suicide at sometime in their life (compared with 44% of the sample as a whole). A similar proportion of those who had experienced violence in the home had attempted suicide (67%) as had 71% of those who had been homeless and 74% of those who had experienced sexual abuse.

- The presence of significant levels of neurotic symptoms, as shown by a CIS-R score of 12 or over, was associated with a four-fold increase in the odds of reporting suicidal thoughts at some time. In contrast having a long-standing physical health problem was associated with a decreased likelihood of reporting suicidal thoughts once other factors had been taken into account. High levels of neurotic symptoms were also associated with suicide attempts and in this case the number of stressful life event also showed a very strong association.

1 Background, aims and method

1.1 Focus of the report

Mental illness was identified as one of the key areas for action in *The Health of the Nation*, a White Paper published by the Department of Health in July 1992 (Department of Health, 1992) and subsequently in *Our Healthier Nation* (Department of Health, 1999a) and *Our National Health: a plan for action, a plan for change* (Scottish Executive, 2000). Frameworks for action have been set out in the *Health of the Nation Mental Illness Key Area Handbook* (Department of Health, 1994), *The Spectrum of Care* (Department of Health, 1996), *A Framework for Mental Health Services in Scotland* (Scottish Executive, 1997) and most recently in the *National Service Framework for Mental Health* (Department of Health, 1999b).

To provide information to support and monitor these initiatives, a series of national surveys of psychiatric morbidity have been carried out by ONS (formerly OPCS) over the past decade, which were commissioned by the Department of Health, the Scottish Executive Health Department and the National Assembly for Wales. These surveys covered a wide range of different population groups. They included:

- adults aged 16–64 living in private households (Meltzer *et al*, 1995a, b, c);
- residents of institutions specifically catering for people with mental health problems: hospitals, nursing homes, residential care homes, hostels, group homes and supported accommodation (Meltzer *et al*, 1996a, b, c);
- homeless adults living in hostels, nightshelters, private sector leased accommodation or roofless people using day centres (Gill *et al*, 1996);
- adults known by services to have a psychotic disorder (Foster *et al*, 1996);
- prisoners (Singleton *et al*, 1998); and
- children and adolescents (Meltzer *et al*, 2000).

The data covered in this report come from two sources: a survey which was carried out in 2000 and is a repeat of the first survey of adults living in private households, and a supplementary sample of people with psychosis identified through GP records. The 2000 survey was a repeat of the 1993 survey of adults in private households but included a number of developments, which are described in more detail in the main survey report (Singleton *et al*, 2001). Most notably, there was a slight increase in the age range, so that it covered people aged 16 up to 74 years, and measures of personality disorder and intellectual functioning were included.

The *National Service Framework for Mental Health* (Department of Health, 1999b) laid down a number of objectives for the improvement of services to those with serious mental illness. These included assessment of service users for antipsychotic medication, access to education, training, occupational and social care support. This report presents information relating to these areas collected from two groups of adults aged 16–74 living in private households who have a psychotic illness.

Bringing together data obtained from people with psychotic disorders identified in the main survey, and from those located through a supplementary sample obtained through general practice records provides a sample of large enough size for separate analysis. The main survey was conducted throughout Great Britain so the sample of people with psychotic disorder will include some people resident in Scotland or Wales. However, the supplementary survey only covered practices in England, so no Scottish or Welsh residents are included in that sample. Hence, the results presented in this report largely relate to residents of England.

The aim of the report is to investigate the circumstances of adults with a psychotic disorder, and to identify characteristics associated with their functioning, circumstances and use of services. The report considers:

- medical treatment including use of psychoactive medication, non-compliance with medication regimes, and use of other forms of treatment;

- use of services, including GP consultations, in-patient stays and outpatient visits, community care services and use of day activity facilities;
- difficulties with activities of daily living, and assistance required and received with these activities;
- social networks and perceived social support;
- economic activity, income and financial difficulties;
- substance misuse: smoking, alcohol consumption and illicit drug use; and
- stressful life events and suicidal thoughts and behaviour.

The current survey is intended to update the information reported in *Adults with a psychotic disorder living in the community* (Foster *et al*, 1996). However, there are important differences between the data presented here and those in that earlier report:

(i) The age range has been extended to include people aged 65–74, who were excluded from the earlier survey.
(ii) The supplementary sample for the 1993 survey was obtained by different methods, discussed in more detail below.
(iii) The 1996 report included a sample of people with a psychotic illness who were identified in a separate survey of people living in communal establishments carried out in 1994, which has not been repeated. This group comprised people living in establishments, such as supported lodgings or small group homes, which met the standard ONS definition of a household. A few people living in this type of accommodation may be in the sample obtained in the 2000 survey or the supplementary sample but no attempt was made to specifically sample this type of accommodation.
(iv) There were some differences in the way in which psychotic disorder was assessed in the 1993 and 2000 surveys of adults living in private households.

1.2 The samples used in this report

The prevalence of psychotic disorder in the general population is about 0.5%, so very large sample sizes would be required to yield sufficient numbers of people with these disorders for detailed analysis.

The main survey identified only 60 people suffering from psychotic illness and it was therefore necessary to identify a supplementary sample of people with psychosis to allow analysis of service use and social and economic functioning among this group. The difficulties associated with obtaining representative samples of people with psychotic disorder in surveys are discussed in more detail in Appendix A.

The supplementary sample aimed to provide a representative sample of people living in the community and known to have a psychotic or other severe mental disorder. Information was collected on the same topics as those covered in the main survey (see below).

Ethical approval for the supplementary survey was obtained from the London Multi-centre Research Ethics Committee and the Local Research Ethics Committees in all areas where the survey was likely to take place.

1.2.1 The supplementary sample

The sample design of the earlier supplementary survey in 1993 involved trying to identify all people with psychosis in the 200 postal sectors selected for the private household sample. Approaches were made to managers of Mental Health Units asking them to identify, with their teams, all individuals who had a psychotic illness living in these postal sectors. GPs with patients in the selected areas were identified by Family Health Service Authorities and were also asked to identify their patients who may have had psychosis and were **not** in contact with secondary services. The people identified in these ways were then approached by the person making the referral, and asked if they would take part in the survey.

However, many Mental Health Care Teams and GPs, especially those without computerised record systems refused to take part, and some details were obtained from only 90 out of the 200 postal sectors. No information was available on the number of people excluded as a result of non-response, nor on their age, sex or condition. Therefore, as well as being extremely time-consuming and expensive, this method provided data from which it was impossible to generalise to the whole population or even to estimate the potential bias in the results.

To try and overcome these problems a different approach was taken in 2000. The sample was obtained from records held by the General Practice Research Database (GPRD). The GPRD is currently owned by the Department of Health and managed by the Medicines Control Agency. However the Office for National Statistics managed the database between 1994 and 1999 and during this time a system of periodic audit of data quality was established, enabling the selection of research quality data. Practices were recruited on a volunteer basis and the population covered is broadly representative of the population of England and Wales.

Participating practices follow agreed guidelines for the recording of clinical data and submit anonymised, patient-based clinical records on a regular basis to the database. The records consist of information that is normally required for general practitioners (GPs) to perform their clinical and contractual responsibilities. As well as recording information on consultations and prescriptions issued by the GP, they will also include detail of referrals to out-patients and the outcome of these and details of, for example, discharge letters received. Diagnostic and treatment data in the GPRD are based on the clinical judgements made by the GPs themselves, or on information given by hospitals or other medical personnel. The GPs contributing to the database are not required to record the reason for every consultation; however they, are required to record all significant morbidity events including date of onset of chronic conditions, prescriptions and the reason for prescribing in certain instances (there is a requirement to specify a reason at the first issue of a repeat prescription and then subsequently only if there is a change to the medication), and referrals.

The quality of data is continually assessed to ensure maintenance of research standards. Data from each practice are routinely examined after each data collection (normally every six weeks) to monitor whether the research recording agreement has been followed. Practices which fail the quality assessment criteria are informed of the areas in which they have failed so that they may improve their recording procedures and/or correct the records as appropriate. Research studies only use data from practices that met quality standards during the time period covered by the study.

It was envisaged that use of the GPRD would overcome some of the problems of the lack of generalisability encountered in the 1994 study. Even if response was still poor, the GPRD would provide some statistical information about the sample which would allow comparisons between subjects who were withdrawn from the survey by their GPs, those who refused on their own behalf and those who responded to the survey.

One hundred and seventy two English GPRD practices were identified as being suitable for inclusion in the sample in that they were active contributors of research quality data to the database at the start of 1998. Initially, practices were ordered by geographical area and size of practice and one in two practices selected alternately from a random start point. The intention was to use the remaining practices as replacements for those who refused to take part.

Ten practices of varying sizes and geographical locations were selected to test the procedures being used. Introductory letters were sent to practices from the GPRD giving a brief description of the survey and seeking practice participation. Five practices were unable or unwilling to participate and were replaced with previously unselected practices. From this pilot phase, agreement was obtained from 7 practices, approximately half of those invited. *(Table 1.1.)*

Once agreement to participate was received from practices, GPRD staff then identified all patients within these practices fulfilling one or more of the following conditions:

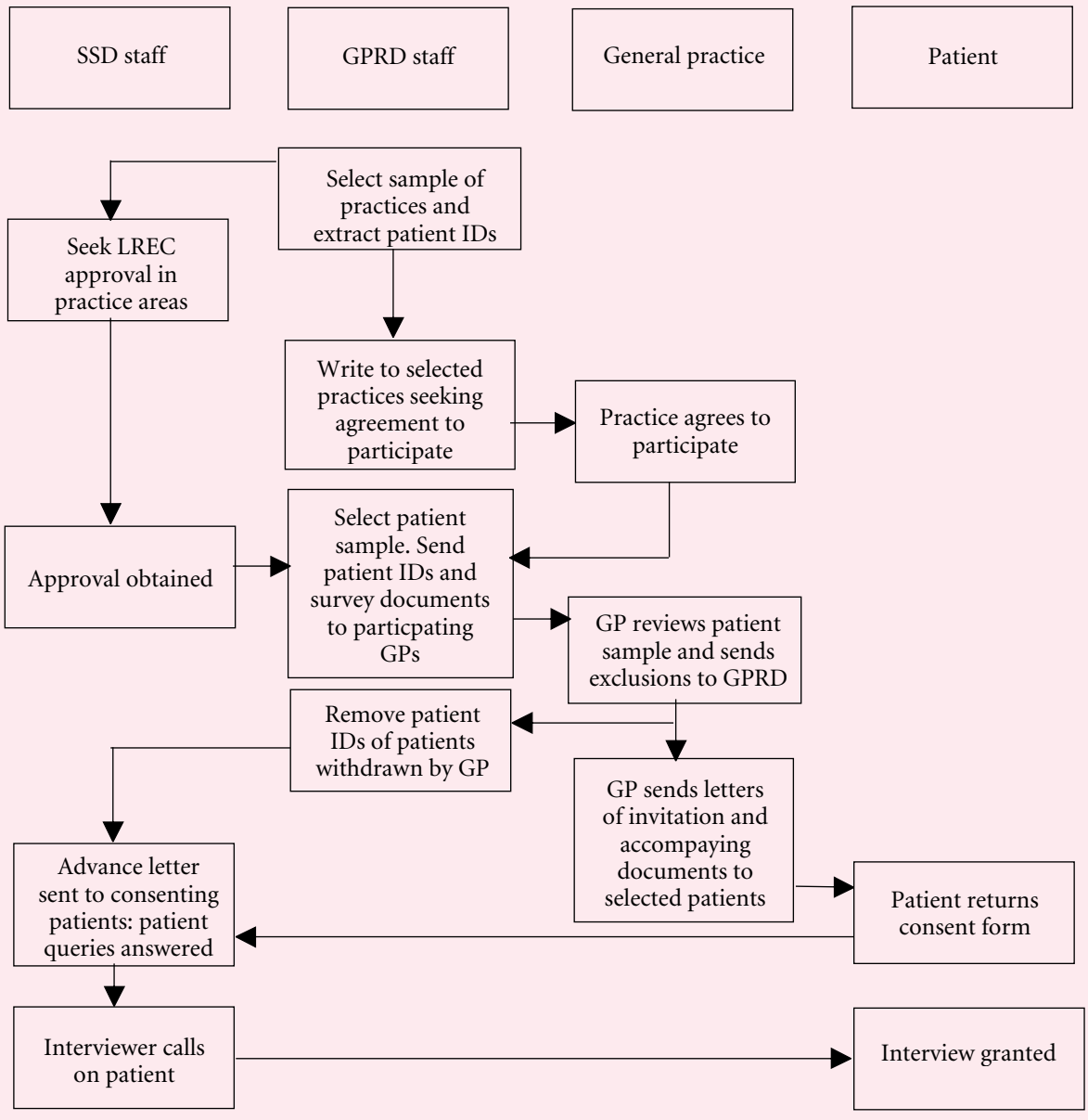
- they had been diagnosed with schizophrenia, either currently or in the past;
- they had been diagnosed with bipolar disorder (manic depression), either currently or in the past; and
- they had been prescribed drugs normally used to treat one of the above disorders, either currently or in the past. People aged 60 and over who were receiving anti-psychotic drugs that are frequently used to treat elderly people suffering from other conditions, such as agitation or restlessness associated with dementia (thioridazine, sulpiride, risperidone, olanzapine and promazine hydrochloride), were excluded from the sample because of the high probability that they were not suffering from a psychotic disorder.

GPRD staff extracted the patient IDs and some basic demographic information for all patients meeting these conditions. The sample of patients for the survey was then randomly selected taking 1 in 2 diagnosed patients and 1 in 20 patients who had received anti-psychotic medication but where no diagnosis of psychotic illness was indicated.

Participating practices were then sent copies of letters of invitation, information leaflets, consent forms and reply-paid envelopes. Patient IDs of those patients included in the sample from their practice were included with this material.

Participating GPs checked that patients on the list were still registered with the practice, and established whether it was appropriate for them to be asked to take part in the survey. They then sent out invitations to their patients asking if they wished to take part in the survey. Patients who were willing to participate returned the informed consent form to SSD (Social Survey Division) in reply-paid envelopes. Because names and addresses were only obtained when people agreed to take part, it was not possible to send reminders to non-responding patients.

Figure 1.1 Flow chart of survey procedures for obtaining the supplementary sample



Shortly before interviewers were due to call, an advance letter was sent to those who had agreed to take part informing them that an interviewer would call (the usual procedure on ONS surveys). This allowed sampled individuals a further opportunity to cancel their participation by telephoning ONS before the interviewer arrived. An overview of the procedures used to obtain the sample for interview is shown in the flow chart in Figure 1.1.

Table 1.2 shows the response from patients within the pilot practices. Just over a quarter (27%) of the respondents were ineligible for the survey, 8% were excluded on health grounds and the remaining 65% were sent invitations. Of those invited in the pilot phase, 18% returned reply slips indicating agreement to participate.

Pilot practices were asked to comment on the procedures used and amendments made as appropriate. Once procedures were finalised, a further 76 practices were approached. The response rates at both practice and patient level at this stage (main stage 1) are shown in Tables 1.1 and 1.2. Because response was lower than we had anticipated, and the rate of ineligibility and exclusions higher, it was decided to contact all remaining unselected practices fitting the criteria agreed with GPRD. It was also clear by this stage that GPs were more likely to exclude patients in the treatment-only group on the grounds of ineligibility, and that response was generally lower among this group. It was therefore decided to include all diagnosed patients in the lists sent to general practices in main stage 2, and to exclude those in the treatment-only group. Overall, response from practices was 37%, while for patients it was 11% of the sample as a whole and 17% of those invited. Response rates of this level are to be expected when patients are asked to opt-in and no reminders are possible since names and addresses are not available to the survey team. *(Tables 1.1–1.3)*

Just over a third (34%) of the patients selected in these responding practices were excluded by GPs, either because they were ineligible or for health reasons. Table 1.4 shows reasons given by GPs for excluding selected patients from the sample. In almost half the cases (48%), the patient was either no longer with the practice or had died. A further one in five (19%) were not suffering from a psychotic illness (many of these had been selected on the basis of prescription only). Eight per cent were not resident in private households, and a similar proportion were excluded for a range of other reasons. Seventeen per cent of those excluded (7% of the sample as a whole) were eligible for the survey, but were felt by their GP to be too ill to participate. *(Table 1.4)*

1.2.2 The private household survey sample

The procedures for identifying people with a psychotic disorder in the main survey are described in some detail in the survey report (Singleton *et al*, 2001) and are summarised below. In the main survey a two-stage approach was adopted to assess the presence of psychotic disorder in the year before interview. In the initial lay interview the following criteria were considered indicative of possible psychotic disorder:

- Self-report, at questions about long-standing illness or reasons for consulting a GP, of symptoms suggestive of psychotic disorder, eg mood swings, or having been given a diagnosis of psychotic disorder, such as schizophrenia or manic depression.
- Taking anti-psychotic medication.
- A history of admission to a mental hospital or ward.
- A positive response to question 5a of the Psychosis Screening Questionnaire (Bebbington and Nayani, 1994) which asks about auditory hallucinations.

A positive response on any one of these criteria led to selection for a second stage interview using the Schedule for Clinical Assessment in Neuropsychiatry (SCAN) (World Health Organisation, 1999). A sample of people who screened negative were also interviewed at the second stage to investigate the likely extent of false negatives: some whom sifted positive for personality disorder and others who screened negative for both types of disorder.

Not all those people who were selected for a second stage interview took part in this stage of the survey, either because they refused a further interview or could not be contacted during the field work period. To obtain an estimate of the prevalence of psychotic disorder based on the whole sample who had undertaken an initial interview, an assessment of probable psychotic disorder was applied to these

people using an algorithm that was first used in the survey of psychiatric morbidity among prisoners (Singleton *et al*, 1998). In the survey of prisoners, data collected from people who had both an initial interview and a second stage SCAN interview were used to identify factors associated with an increased likelihood of receiving a SCAN assessment of psychotic disorder. This found that the presence of any two of the criteria used for the initial screening for SCAN interview as described above, was indicative of a probable psychotic disorder.

Therefore, in the current survey, an assessment of probable psychosis was given to those who screened positive for psychosis and were either assessed as having a psychotic disorder at SCAN interview or, if no SCAN interview had been conducted, who reported two or more of the above criteria at initial interview. People who screened negative for psychosis were designated unlikely to have psychotic disorder. For more details about the assessment of psychotic disorder in the survey and the rationale for this approach see Appendix A of this report and also the report of the 2000 survey (Singleton *et al*, 2001).

1.3 Representativeness of the supplementary sample

Response to the survey was low, so care must be taken in interpreting the results presented in this report. It is possible to get an idea of the extent to which the people interviewed in the supplementary sample were representative of all people with psychotic disorders registered with GPs in England in two ways. Firstly, by considering the representativeness of the practices that contribute to the GPRD and secondly, by comparing those who took part in the survey with those who did not.

Practices that contribute to the GPRD must be computerised and prepared to maintain their records to strict quality standards. Therefore, they may not be representative of all GP practices. Practice size ranges from single handed to six or more partners, with a slightly larger proportion of GPRD practices having four or more partners than is the case nationally and correspondingly fewer single-handed GPs. However a comparison of the 1998 GPRD population by age and sex with the population of England and Wales shows the age distributions to be broadly similar.

There is some variation in coverage between NHS Regional Office areas from 1.4% in North Thames to 3.6% in West Midlands (Office for National Statistics, 2000). This publication also describes GPRD distribution by ONS area classification and deprivation categories. Despite these factors, a study carried out in 1994 (Hollowell, 1997) comparing GPRD data with MSGP4 (Morbidity Statistics from General Practice: Fourth National Study 1991–2) data found good agreement in, for example, rates for treated asthma. The database has been widely used in epidemiological research studies.

To allow sampling for the survey, some basic anonymised data were obtained for all patients meeting our sampling criteria for psychotic disorder in those practices eligible to take part in the survey. The data for practices that agreed to participate in the survey and those that did not were compared to check for any possible non-response bias arising as a result of refusals at the practice level. In practices which refused to take part there were slightly more older people meeting our sampling criteria and a slightly smaller proportion with no diagnosis but selected on the basis of prescription only. However, the differences were small and unlikely to be important. *(Table 1.5)*

Non-response among patients in participating practices, either through exclusions by GPs or from non-response by invited patients is another possible source of non-response bias. In order to identify the likely extent of any such bias the characteristics of people who took part in the survey were compared with those that did not for different reasons. This revealed a few differences between those who agreed to interview and those who were not interviewed because of refusal, ineligibility or because the GP felt that they were unsuitable for interview on health grounds. These are shown in Table 1.6. It can be seen that patients who were withdrawn by their GP on health grounds were more likely to be aged under 25 or 55 and over. There was also slightly higher proportion of people with a diagnosis of schizophrenia and smaller proportion with bi-polar disorder among those withdrawn on health grounds. There was a higher proportion of people with bi-polar disorder in the group who agreed to interview compared with those who refused, and a correspondingly higher proportion of people who were receiving

anti-manic medication. However, there were no other notable differences between the two groups. *(Table 1.6)*

Exclusion of people on health grounds may have led to some of the more severe cases being excluded from the sample, although the health problems may have been related to disorders to other than psychotic disorders, for example, dementia among elderly respondents. The high rate of exclusions and non-response means that the sample is not directly representative of all people with psychotic disorders living in private households and care must be taken in interpreting the results presented in this report. However, it is likely that the circumstances and experiences described are similar to those of a large proportion of that population and the broad picture obtained is fairly typical.

1.4 Characteristics of supplementary sample and main sample respondents

Table 1.7 compares some of the characteristics of the main and supplementary samples of people with psychosis. There appear to be a number of differences between the two samples but, because the numbers are small, the only difference that is statistically significant is in defacto marital status: the proportion of divorced and separated people is higher in the main survey group (37%) compared with the supplementary sample (18%) and that of married and cohabiting people is lower (28% compared with 49%). *(Table 1.7)*

1.5 The questionnaire

The same questionnaire was used for people in the supplementary sample obtained from the GPRD as in the main survey of psychiatric morbidity among adults living in private households. Details of the interviewing procedures and the questionnaire used for the main survey can be found in the Technical Report of the survey (Singleton *et al*, 2002) available on the National Statistics website (www.statistics.gov.uk).

The topics covered in the survey are shown below:

(a) Assessments of mental health problems
- Neurotic symptoms and disorders – using the Clinical Interview Schedule, revised version (CIS-R).
- Psychotic symptoms.
- Personality disorder.
- Suicidal thoughts and attempts.
- Alcohol misuse and dependence.
- Drug misuse and dependence.

(b) Other topics covered by the survey
Questions to gather information on a range of factors that might be related to mental disorder were also included in the survey questionnaire. The topics covered were:

- General health and service use:
  - self-perceived health status: the SF-12 and long-standing illness;
  - medication and service use – GP, in-patient, out-patient, day care and community care; and
  - lifetime experience of treatment in mental hospitals/wards.
- Socio-demographic data:
  - personal characteristics: eg age, marital status, ethnicity.
- Education and employment.
- Finances – income and debt.
- Accommodation – tenure, stability, quality.
- Stressful life events experienced.
- Social networks and social support.
- Activities of daily living and need for informal care.
- Intellectual functioning
  - New Adult Reading Test (NART); and
  - TICS-m and animal naming test (adults aged 60 and over).

1.6 Analysis methods

The sample used in this report has been drawn from two surveys, involving differing methods and probabilities of selection. For such a small sample, re-weighting in an attempt to produce population estimates would be unlikely to render accurate results, and it has not been attempted. Percentages presented in this report are therefore indicators of prevalence only within this particular sample, and should not be taken as estimates for the total population of people with a psychotic disorder. However, as mentioned earlier, the sample is likely to be typical of many of the people with psychotic disorders within the household population and to represent people across the whole range of severity of disorder.

The sample is useful in allowing us to investigate whether different characteristics are associated with different behaviours or circumstances of people with psychosis and provides a rough guide to the possible levels of service use and social and economic circumstances of people with psychotic disorder living in private households. Differences in service use and other circumstances have been investigated by means of multi-variate analysis. This can be used to indicate groups with different probabilities of the event under investigation, although odds ratios from the sample models should not be seen as estimates for the whole population. Where an association is said to be statistically significant this refers to comparisons within this sample only and does not indicate that the same association would be found to be significant within the whole population of people with psychotic disorder.

The main method of analysis used throughout this report is multiple logistic regression. This method identifies which of a set of independent variables, or characteristics of people in the sample, are associated with a dichotomous dependent variable. The dependent variables were set up to indicate the presence or absence of a particular behaviour or state, for example, respondent was on prescribed medication versus not on medication, or informant was a heavy smoker versus not a heavy smoker. The analysis identifies which of the independent variables included in the analysis are most strongly associated with the dependent measure, after controlling for the effect of the other variables in the model. A forward stepwise method of analysis was used. All models used the following set of independent variables which included a variety of sociodemographic variables and indicators of the person's physical health and level of neurotic symptoms such as anxiety and depression (CIS-R score):

- Sex — male; female
- Age — under 45; 45–74
- Marital status — married or cohabiting; single; widowed, divorced, separated
- Educational qualifications — 'A' levels and over; Other; None
- Economic status — economically active; economically inactive
- Social class — I,II,IIINM; IIM, IV, V; other, not known
- Tenure — owner; renter
- Household size — 1; 2; 3 and over
- CIS-R score — below 12; 12 and over
- Long standing physical illness — none; one or more
- Sample group — supplementary sample; main survey sample

As described in section 1.4, there were some possible differences between the sample of people obtained from the main survey and those from the supplementary sample. However, the small number of people, particularly in the main survey group means that these differences were generally not statistically significant and also makes it inappropriate to present results for the two groups separately as apparently large differences may well occur by chance. However, a variable indicating the sample group from which the case came was included in all the logistic regression analyses to identify any areas in which the two samples differed from each other.

Tables showing the results of the logistic regression analyses list only those characteristics that were significantly associated with the dependent variable, although all variables shown above were included in the analysis. An example of the results obtained from these analyses is shown in Table 2.10 (page 22). In this case, in the first column of results, the dependent variable is whether the respondent had talked to a GP in the past year about a mental or emotional problem. Two variables, age group and level of neurotic symptoms (CIS-R score), were included in the final model. This showed that each of these factors was, after allowing for the effects of the other, significantly associated with the probability of consulting a GP. For each variable in the model, the logistic regression produces an estimate of the odds of the event occurring for an individual in each category. The tables in this report show the odds ratio for each category of the independent variables included in the final models.

This is derived by dividing the odds for that category by the odds for a defined reference category. Where more than one independent variable is included in the model, the odds and odds ratios are adjusted for the effects of the other variables in the model. In Table 2.10 the adjusted odds ratio for people with a CIS-R score of 12 and over is 2.72. Thus the odds of having consulted a GP were almost three times higher for this group than for people with lower levels of neurotic symptoms and a CIS-R score below 12. Odds ratios that are significantly different from those of the reference category for that variable are indicated with asterisks in the tables. More information on logistic regression analysis and the interpretation of odds ratios can be found in Appendix B.

Table 1.1 Response at different stages of the survey – general practices

	Practices approached Number	Practices responding Number	Percentage of practices approached
Pilot	15	7	47
Main stage 1	76	29	38
Main stage 2	81	27	33
Total	172	63	37

Table 1.2 Patient outcome by basis for selection

	Basis for selection		
	Diagnosis	Prescription only	Total
	%	%	%
Outcome			
Cooperating	12	5	11
Non-cooperating	56	49	55
Excluded on health grounds	7	7	7
Ineligible	25	39	27
Base (all sampled)	*1244*	*152*	*1396*

Table 1.3 Response at different stages of the survey – patients

	Pilot	Main stage 1	Main stage 2	Total
	%	%	%	%
Invitation sent	65	66	67	66
Excluded on health grounds	8	7	7	7
Ineligible	27	27	26	27
Base (patients sampled)	*78*	*589*	*729*	*1396*
	Percentage of patients invited			
Patients consenting	18	15	18	17
Base (patients invited)	*51*	*389*	*489*	*929*

Table 1.4 Reasons for patients being withdrawn from the sample

Reason given for excluding patient	%
Patient is no longer registered with practice	43
Patient does not have a psychotic illness	19
Current health of patient makes him/her unsuitable for inclusion	17
Patient is not resident in a private household	8
Patient has died	5
Other reason	8
Base	*553*

Table 1.5 Characteristics of patients in co-operating and non-co-operating practices

	Practice outcome		
	Agreed to participate	Refused to participate	All practices
	%	%	%
Sex			
Male	51	53	52
Female	49	47	48
Age			
16–24	2	1	1
25–34	13	11	12
35–44	20	20	20
45–54	24	23	23
55–64	20	23	22
65–74	20	22	21
Diagnosis			
Schizophrenia	55	58	57
Bi-polar disorder	28	26	27
Both	6	8	7
No diagnosis	11	7	9
Grounds for patient selection			
Diagnosis only	17	20	19
Prescription only	11	7	9
Diagnosis and prescription	72	72	72
	Percentage who had received each medication		
Prescriptions			
Anti-psychotic medication	79	76	77
Anti-manic medication	24	21	22
Base	*1396*	*2051*	*3447*

Table 1.6 Characteristics of co-operating and non-co-operating patients – supplementary sample

	Patient outcome				
	Agreed to interview	Refused interview	Withdrawn on health grounds	Ineligible	All
	%	%	%	%	%
Sex					
Male	49	51	49	53	51
Female	51	49	51	47	49
Age					
16–24	-	1	5	2	2
25–34	11	12	9	18	13
35–44	23	21	20	19	20
45–54	28	26	16	21	24
55–64	21	22	23	16	20
65–74	17	19	27	24	20
Diagnosis					
Schizophrenia	49	55	60	55	55
Bi-polar disorder	42	28	20	25	28
Both	4	8	9	4	6
No diagnosis	6	9	11	16	11
Grounds for patient selection					
Diagnosis only	15	17	15	19	17
Prescription only	6	9	11	16	11
Diagnosis and prescription	79	74	74	65	72
			Percentage who had received each type of medication		
Prescriptions					
Anti-psychotic medication	76	80	81	76	79
Anti-manic medication	33	24	19	20	24
*Base**	*140*	*790*	*373*	*93*	*1396*

* Patients from cooperating practices only.

Table 1.7 Characteristics of main sample and supplementary sample

	Main survey sample	Supplementary sample	All
	%	%	%
Sex			
Male	50	48	48
Female	50	52	52
Age			
16–24	3	1	2
25–34	18	9	12
35–44	30	25	26
45–54	25	28	27
55–64	13	22	20
65–74	10	15	14
Marital status			
Married/cohabiting	28	49	43
Divorced/separated	37	18	24
Widowed	5	6	6
Single	30	26	28
Employment status			
Working full time	7	16	13
Working part time	14	14	14
Unemployed	2	4	3
Economically inactive	77	67	70
Social class			
I,II	18	26	24
IIINM	18	28	25
IIIM	17	13	14
IV	17	21	20
V	18	10	12
Not known	12	2	5
Base	*60*	*140*	*200*

2 Medication, treatment and use of services

2.1 Introduction

This chapter looks at the extent to which people with a psychotic illness had used medication, other forms of treatment and accessed a range of services. It also examines whether those on treatment reported compliance with the treatment regimes, whether treatment had been offered and refused and, if so, why this decision was made.

The survey collected information about medication used in the treatment of psychiatric disorders prescribed to informants at the time of interview. The medicines were coded according to the British National Formulary (British National Formulary 2000). The categories considered were:

- drugs used for the treatment of psychotic illness, including antipsychotic drugs, antipsychotic depot injections and antimanic drugs (for simplicity this whole group of drugs may sometimes be referred to as antipsychotic medication in this chapter);
- antidepressants; and
- hypnotics and anxiolytics.

Other forms of treatment fall into two broad categories: psychological therapy and counselling. These included psychotherapy, behavioural or cognitive therapy, art music or drama therapy, social skills training, marital or family therapy, sex therapy and counselling.

The section on service utilisation covers: GP consultations, in-patient episodes, out-patient or day-patient visits, community care services and day activity services.

2.2 Treatment

Overall, 91% of respondents were receiving some form of treatment. When considering the proportion receiving treatment, it should be remembered that, in the main survey, one of the four criteria used to identify people likely to have psychosis was the receipt of drugs used for treating psychotic illnesses. Also the receipt of such drugs at some time was one way in which people were identified from the GPRD for inclusion in the supplementary sample. This might tend to inflate the proportion of people receiving treatment in the sample. However, antipsychotic medication alone was not sufficient to provide an assessment of disorder, and a history of a diagnosis or treatment of disorder rather than current treatment was used as a criteria for selection from the GPRD, specifically so people who had slipped out of treatment or may have recovered would also be included in the sample.

There were no differences in the proportions receiving any type of treatment in terms of sex and age. However, those aged 45 and over, were more likely than younger respondents to be receiving medication only (68% compared with 55%). Among the younger respondents, 6% were receiving a psychological therapy or counselling only, compared with 1% of those aged 45 and over. Although similar proportions of each age group were receiving medication, among the younger respondents over a third (39%) were receiving counselling or other psychological therapy, either alone or with medication, compared with just over a fifth (22%) of those aged 45 and over. *(Table 2.1)*

2.2.1 Medication use

Just over four-fifths (82%) of respondents were receiving one or more of the medications considered in this section. The majority of these, 63% of the sample as a whole, were taking drugs used in the treatment of psychoses, over a third of the sample (37%) were taking antidepressant medication, and just over a fifth (22%) were taking hypnotics or anxiolytics.

Men were more likely than women to be taking medication used for treating psychotic disorders – 71% compared with 55%. Younger informants, those under 45, were more likely to report that they were receiving antidepressant medication; 48% of this group reported taking antidepressants, compared with 30% of those aged 45 and over. *(Table 2.2)*

Logistic regression was used to investigate which characteristics were most strongly associated with being on drugs used to treat psychoses and antidepressant medication. Further information on this method of analysis and the variables used in the analysis is given in Chapter 1 and Appendix B. As shown in Table 2.3, four variables were independently associated with being on medication used for the treatment of psychoses: sex, employment status, whether the informant had a long-standing physical illness and CIS-R score. The association was strongest for employment status and CIS-R score. The odds of those with significant levels of neurotic symptoms, as shown by CIS-R scores of 12 and over, being in receipt of antipsychotic medication were less than one third of those with scores below 12. The medication being prescribed, however, by controlling symptoms may have an effect on CIS-R scores. Those who were economically inactive had odds over three times greater than those who were economically active of being prescribed drugs used to treat psychoses. It should be remembered that no causal relationship or direction is implied by these odds, and in the case of employment status, it is likely that the severity of illness affects both the likelihood of being on antipsychotic medication and being unable to work. This survey did not include any estimation of the severity of the psychotic illness.

Of the variables included in the analysis, only age and CIS-R score were associated with being on antidepressant medication once the effects of the other variables in the model are controlled for. Again, the strongest association was with CIS-R score but in this case those with higher levels of neurotic symptoms were more likely to be on medication. For antidepressant medication, the odds that those with scores of 12 and over were having antidepressant medication were almost three times greater than those of people with scores below 12. *(Table 2.3)*

2.2.2 Depot injections

Antipsychotic medication may be administered by injections at regular intervals. These are often termed depot injections. Respondents were asked whether they were receiving any medication by injection and, if so, what. In this sample, 10% of people who were using antipsychotic medication were receiving them as depot injections. This is substantially fewer than was found in the sample from the 1993 surveys, when a quarter of the sample living in private households were receiving antipsychotic depot injections (Foster *et al*, 1996).

People aged under 45 were less likely to be receiving their antipsychotic medication in the form of depot injections than older people, 2% were receiving depot injections compared with 14% of those aged 45 and over. Logistic regression analysis showed only age group to be significantly and independently associated with receiving antipsychotic medication in the form of depot injections. *(Tables 2.4 and 2.5)*

2.2.3 Compliance with medication

Informants were asked whether they sometimes did not take medication which had been prescribed for their condition even though they should, or whether they ever took more than had been prescribed. Just under a third of respondents who were taking psychoactive medication (32%) had sometimes not taken their medication when they should have, and 20% reported that they had taken more of the medication than the prescribed dose.

Those under 45 were more likely to report non-compliance with medication than were older respondents. Forty eight percent of the younger informants reported that they sometimes did not take medication when they should, compared with 21% of those aged 45 and over. Younger respondents were also more likely to report taking more than the stated dose of medication, although this difference did not achieve statistical significance. *(Table 2.6)*

Two variables were independently associated with not taking psychoactive medication: age and social class. Those under 45 had odds over three times those of older informants of sometimes not taking their medication, while those in manual social classes (which included those who had never worked) also had increased odds of not always taking their medication. The only variable independently associated with taking more than the prescribed dose of medication was CIS-R score. *(Table 2.7)*

2.2.4 Psychological therapy or counselling

Respondents were shown a card listing different types of psychological therapy and asked if they were currently receiving any of these or similar treatments. As mentioned at the start of section 2.2, 29% of the people in this sample said they were receiving some form of psychological therapy or counselling either alone or as well as psychoactive medication. This is somewhat lower than reported for the small group of people with psychotic disorder from the main survey sample alone (40%) (Singleton *et al*, 2001, Table 5.13), suggesting some difference between the two groups included in this report with respect to these types of treatment. This should be borne in mind when considering the results presented here. Table 2.8 shows the different types of therapy reported by those who were having these types of treatment. The most frequently mentioned group was psychotherapy or psychoanalysis, reported by almost half (49%) of those receiving counselling or other psychological therapy. Over two-fifths (42%) of informants having one of these types of treatment were receiving counselling, and 14% were being treated through behavioural or cognitive therapy. Other types of therapy were relatively rare. *(Table 2.8)*

2.3 Contact with health and other services

The analysis in this section covers four categories of services: GP consultations, in-patient episodes and day- or out-patient visits, community care services and the use of day activity facilities. It is probable that the use of some of these services will vary according to the characteristics of informants, such as their age and living arrangements. As in other sections, logistic regression was used to identify which of the characteristics recorded by the survey were independently associated with service usage.

We would also expect that use of services might be related to the severity and time since onset of a person's condition. However, as we do not have information on these factors for the whole survey sample, the analysis cannot control for these factors and the interpretation of results should take account of possible relationships of this type.

2.3.1 GP consultations

Informants were asked whether they had consulted a GP in the last year, or in the last two weeks for either a physical, or a mental, nervous or emotional problem. Consultations included those made in person or by telephone. This analysis concentrates on consultations for mental health problems.
In the year before the interview, three-fifths (62%) of respondents had consulted their general practitioner about a mental or emotional problem and 10% had done so in the past two weeks. However, there was significant variation with age. Three quarters (75%) of those under 45 had consulted their GP in the past year, compared with only just over half (54%) of respondents aged 45 and over. Younger respondents were also more likely to have consulted their GP in the two weeks before interview. Overall, one in ten patients had done so, but among younger respondents almost one in six (16%) had consulted the GP in the last two weeks, compared with only 6% of those aged 45 and over. There were no significant differences between men and women in the proportion consulting the GP. *(Table 2.9)*

Logistic regression analysis showed that the characteristics independently associated with having talked to the GP in the previous twelve months about mental or emotional problems were age and CIS-R score. The odds of those aged over 45 having spoken to the GP were less than half those of informants under 45. The odds of those with CIS-R scores of twelve or more having spoken to the GP in the previous twelve months about a mental or emotional problem were almost three times greater than those for people with lower scores. *(Table 2.10)*

2.3.2 In-patient stays and out-patient or day-patient visits

Overall, 3% of the sample reported an in-patient stay in the last quarter relating to a mental health problem. Because of the small proportion of respondents reporting in-patient stays it is difficult to examine the relationship between in-patient stays and other factors. *(Table 2.9)*

Out-patient or day-patient visits were reported more frequently than in-patient stays. Over a fifth of the sample (22%) reported one or more such visits in the past quarter. Younger respondents were almost twice as likely as those aged 45 and over to do so (30% compared with 17%). *(Table 2.9)*

Logistic regression analysis was carried out to identify factors independently associated with attending an out-patient department because of a mental or emotional problem. Only age was associated with outpatient attendance in connection with a mental or emotional problem in the past three months in this group of people with a psychotic disorder: the odds of older people attending outpatients being half that of younger people. *(Table 2.10)*

2.3.3 Community health and support services

Informants were asked whether they had used any of a range of community health and support services in the three months before interview. They were asked to exclude contacts with professionals that they had already mentioned in connection with in-patient stays or out-patient visits. The services listed were:

- psychiatrist;
- psychologist;
- community psychiatric nurse;
- community learning difficulties nurse;
- other nursing services;
- self-help or support group;
- social worker;
- home help or care worker; and
- outreach worker or family support.

Overall, two-fifths (40%) of the adults in this sample of people with a psychotic disorder had had some contact with one or more of these services during the previous quarter. There were no differences by sex or age in the proportions of people who had used any of the community services. *(Tables 2.11)*

Receipt of any community care services in the past twelve months was independently associated with living alone and economic inactivity. People living alone had almost two and a half times greater odds of receiving these services than those who were living with others, while those who were economically inactive had twice the odds of the economically active of receiving such services. These associations were even stronger when the analysis was limited to visits from a community psychiatric nurse. *(Table 2.12)*

2.4 Day activity services

Respondents were asked whether they had used any of a range of day activity services in the previous twelve months. The services were:

- A community mental health centre.
- A day activity centre.
- A sheltered workshop.

Respondents who reported use of any of these services were then asked whether they had used them during the last quarter.

Overall, over a quarter (27%) of informants had used one or more day activity services in the previous year, and 20% in the three months before interview. Men were twice as likely than women to have used a day activity service in the past year, 38% had done so, compared with 17% of women. *(Table 2.13)*

Logistic regression analysis showed that use of day activity services was independently associated with sex, household size and social class. Women had odds only a quarter of those of men of having used any day activity services in the year before interview. The association with household size was also very strong. People living alone had more than three times greater odds of using day activity services than those living with other people. The association with social class was less strong, but still significant. People in manual social classes were more likely than those in non-manual classes to have used a day activity service once the other factors were taken into account. *(Table 2.14)*

Separate analyses of factors associated with the use of community mental health centres and day centres (the two main types of day activity services used) found that sex, household size and sample group were independently associated with using community mental health centres. Men, people living alone and those in the main survey sample

had greater odds of having attended a community mental health centre. Sex and employment status were associated with day centre use: Men and people who were economically inactive having greater odds of attending. *(Table 2.14)*

A count of the number of services received by each individual is shown in Table 2.14 to provide an indication of the extent to which people accessed the full range of services possible. The services included in the count were:

- consultations with a GP in the past year for a mental problem;
- inpatient stays for a mental or emotional problems in the past quarter;
- out- or day-patient visits for mental or emotional problems in the past quarter;
- community care service receipt in the past quarter; and
- day activity service use in the past quarter.

Just under a quarter of the sample (24%) had not received any of these services and slightly more than a third (36%) had received only one. About half of the remainder (22% of the sample as a whole) reported having received three or more of the types of services covered. Men in the sample were a little more likely than the women to have received two or more services, while older people were less likely to report receiving any of the services and also less likely to be receiving two or more. *(Table 2.15)*

2.5 Help not sought and services turned down

Everyone taking part in the survey was asked if there were any times in the past year when they had not sought help from a doctor or other professional when they or others thought they should have done so, or when they had been offered such help but had turned it down. Overall, 16% of this group of people with a psychotic disorder said they had decided not to see a doctor or other health professional when perhaps they should have but only 8% said they had refused help that was offered. The main reasons given for not seeking help were that they did not think anyone could help and that they were afraid of possible treatment or tests. People with high levels of neurotic symptoms as shown by CIS-R scores of 12 and over had increased odds of not seeking help once other factors were taken into account. The type of help most often mentioned as offered but refused was counselling. *(Tables 2.16 and 2.17)*

Table 2.1 Treatment received by adults with a psychotic illness

by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
	%	%	%	%	%
Current treatment					
None	9	9	6	11	9
Medication only	64	61	55	68	62
Counselling or therapy only	2	4	6	1	3
Medication and counselling/therapy	25	26	33	21	26
Base	*97*	*103*	*80*	*120*	*200*

Table 2.2 Medication prescribed

by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
	Percentage using the medication				
Drugs used in psychoses etc.	71	55	59	66	63
Antidepressants	31	43	48	30	37
Any antipsychotic or antidepressant medication	**82**	**79**	**81**	**80**	**80**
Hypnotics and anxiolytics	26	17	21	22	22
Any psychoactive medication	**86**	**80**	**82**	**82**	**82**
Base	*97*	*103*	*80*	*120*	*200*

Table 2.3 Odds ratios for characteristics associated with treatment with different types of medication

	Drugs used in psychoses etc	Antidepressant medication
	Adjusted odds ratios	
Sex		
Female	1.00	
Male	2.14*	
Age group		
Under 45		1.00
45 and over		0.54*
Employment status		
Economically active	1.00	
Economically inactive	3.45**	
CIS-R score		
Below 12	1.00	1.00
12 and over	0.28***	2.74**
Long standing physical complaints		
Absent	1.00	
Present	0.47*	
Other factors entered in the models but not significantly associated with any dependent variable	Marital status, social class, educational qualifications, 1 person household, tenure, sample group	

*p<0.05 **p<0.01 ***p<0.001

Table 2.4 Mode of administration of antipsychotic medication by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
	%	%	%	%	%
Depot injections	13	5	2	14	10
Oral medication only	87	95	98	86	90
Base	*69*	*57*	*47*	*79*	*126*

Table 2.5 Odds ratios for characteristics associated with receipt of antipsychotic medication by depot injection

	Antipsychotic medication by depot injection
	Adjusted odds ratios
Sex	
Female	1.00
Male	3.80
Age group	
Under 45	1.00
45 and over	9.82*
Other factors entered in the model but not significantly associated with the dependent variable	Marital status, social class, educational qualifications, 1 person household, tenure, long-standing physical complaint, CIS-R score, employment status, sample group

*p<0.05 **p<0.01 ***p<0.001

Table 2.6 Non-compliance with medication dosage by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
	Percentage reporting non-compliance with dosage				
Sometimes does not take medication	36	28	48	21	32
Sometimes takes more than the stated dose	22	18	24	17	20
*Base**	*83*	*82*	*66*	*99*	*165*

* All people on antipsychotic, antidepressant, hypnotic or anxiolytic medication, orally or by injection.

Table 2.7 Odds ratios for characteristics associated with non-compliance with dosage of psychoactive medication

	Sometimes did not take psychoactive medication	Sometimes took more than prescribed
	Adjusted odds ratios	
Social class		
Manual	2.09*	
Non-manual	1.00	
Age group		
Under 45	1.00	
45 and over	0.28***	
CIS-R score		
0–11		1.00
12 and over		2.61*
Other factors entered in the models but not significantly associated with any dependent variable	Sex, marital status, educational qualifications, 1 person household, tenure, long-standing physical complaint, CIS-R score, employment status, sample group	

"*=p<0.05, **=p<0.01, ***=p<0.001"

Table 2.8 Types of therapy or counselling being undertaken

by those receiving such treatment

	Percentage reporting each type of therapy
Psychotherapy or psychoanalysis	49
Counselling	42
Behavioural or cognitive therapy	14
Art, music or drama therapy	7
Social skills training	5
Marital or family therapy	2
Other therapy	9
Base (all having therapy)	*57*

Table 2.9 Health care services used for mental and emotional problems

by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
	Percentage reporting using each service				
GP consultations					
... in last year	64	61	75	54	62
... in past 2 weeks	9	11	16	6	10
Inpatient stay in past quarter	5	1	1	4	3
Outpatient visit in past quarter	26	18	30	17	22
Base	*97*	*103*	*80*	*120*	*200*

Table 2.10 Odds ratios for characteristics associated with use of health care services

	Talked to GP about mental problem in past year	Visited out-patients in past quarter
	Adjusted odds ratio	
Age group		
Under 45	1.00	1.00
45 and over	0.44*	0.47*
CIS-R score		
Below 12	1.00	
12 and over	2.72**	
Other factors entered in the models but not significantly associated with any dependent variable	Sex, marital status, social class, educational qualifications, 1 person household, tenure, long-standing physical complaint, employment status, sample group	

*p<0.05 **p<0.01 ***p<0.001

Table 2.11 Use of community health services in the last quarter by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
	Percentage using each service				
Community care services used					
Community psychiatric nurse	29	17	21	24	23
Psychiatrist	21	17	20	18	18
Social worker	14	6	15	7	10
Self-help or support group	9	5	5	8	7
Home help/care worker	5	4	5	4	4
Psychologist	3	2	4	2	2
Other nursing services	1	3	5	-	2
Outreach worker/family support	3	1	4	1	2
Any community care used in the last quarter	**43**	**37**	**44**	**38**	**40**
Base	*97*	*103*	*80*	*120*	*200*

Table 2.12 Odds ratios for characteristics associated with use of community care services in the past quarter

	Visited by CPN in the community	Any community care services used
	Adjusted odds ratios	
One person household		
No	1.00	1.00
Yes	3.72***	2.54**
Employment status		
Economically active	1.00	1.00
Economically inactive	4.35**	2.23*
Other factors entered in the models but not significantly associated with any dependent variable	Sex,age group, marital status, social class, educational qualifications, tenure, long-standing physical complaint, CIS-R score, sample group	

*p<0.05 **p<0.01 ***p<0.001

Table 2.13 Use of day activity services by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
			Percentage using each service		
In the last year used					
... a community mental health centre	24	11	24	12	17
... a day activity centre	19	7	14	12	12
... a sheltered workshop	4	-	4	1	2
... other day activity service	1	1	-	2	1
Any day activity service used in the last year	**38**	**17**	**32**	**23**	**27**
In the last quarter used					
... a community mental health centre	12	8	12	8	10
... a day activity centre	13	6	10	9	10
... a sheltered workshop	3	-	2	1	2
... other day activity service	-	1	-	1	0
Any day activity service used in the last quarter	**26**	**14**	**21**	**18**	**20**
Base	*97*	*103*	*80*	*120*	*200*

Table 2.14 Odds ratios for characteristics associated with use of day activity services in the past year

	Use of mental health centre in the past year	Use of day centre in the past year	Use of day activity services in the past year
	Adjusted odds ratio		
Sex			
Female	1.00	1.00	1.00
Male	2.38*	3.08*	2.50*
One person household			
No	1.00		1.00
Yes	2.43*		3.32**
Social class			
Non-manual			1.00
Manual			2.20*
Employment status			
Economically active		1.00	
Economically inactive		11.41*	
Sample group			
Supplementary sample	1.00		
Main survey sample	3.02**		
Other factors entered in the models but not significantly associated with any dependent variable		Age group, marital status, educational qualifications, tenure, long-standing physical complaint, CIS-R score	

*p<0.05 **p<0.01 ***p<0.001

Table 2.15 Count of number of services received by sex and age

	Sex		Age		
	Male	Female	Under 45	45 and over	All
			Percentage using each service		
Number of services used					
None	23	24	14	30	24
1	28	45	36	37	36
2	24	14	24	15	18
3	15	12	19	10	14
4	9	5	6	8	7
5	1	1	1	1	1
Base	*97*	*103*	*80*	*120*	*200*

Table 2.16 Help turned down or not sought in the past year by sex and age

	Sex		Age group		
	Male	Female	Under 45	45 and over	All
	Percentage reporting in the past year				
Offered help/services which have been turned down	5	10	9	7	8
Decided not to see a doctor	11	20	24	11	16
Base	*96*	*103*	*80*	*119*	*199*

Table 2.17 Odds ratios for characteristics associated with not consulting a doctor in the past year

	Decided not to see a doctor
	Adjusted odds ratio
CIS-R score	
Under 12	1.00
12 and over	6.94***
One person household	
No	1.00
Yes	0.41
Other factors entered in the model but not significantly associated with the dependent variable	Sex,age group, marital status, social class, employment status, educational qualifications, tenure, long-standing physical complaint, sample group

*p<0.05 **p<0.01 ***p<0.001

3 Activities of daily living

3.1 Introduction

A set of questions asked respondents whether they had any difficulties with a list of activities of daily living. The questions covered the types of activities listed below.

- Personal care, such as dressing, washing, bathing, using the toilet.
- Using transport to get out and about.
- Medical care, taking medicines and pills, having injections or changing dressings.
- Household activities, such as preparing meals, shopping, laundry and housework.
- Practical activities, like gardening, decorating and doing household repairs.
- Dealing with paperwork, for example, writing letters, sending cards or filling in forms.
- Managing money – budgeting for food and paying bills.

Respondents who reported difficulty with any of these activities were asked whether they needed help with the activities, and if so, who provided it.

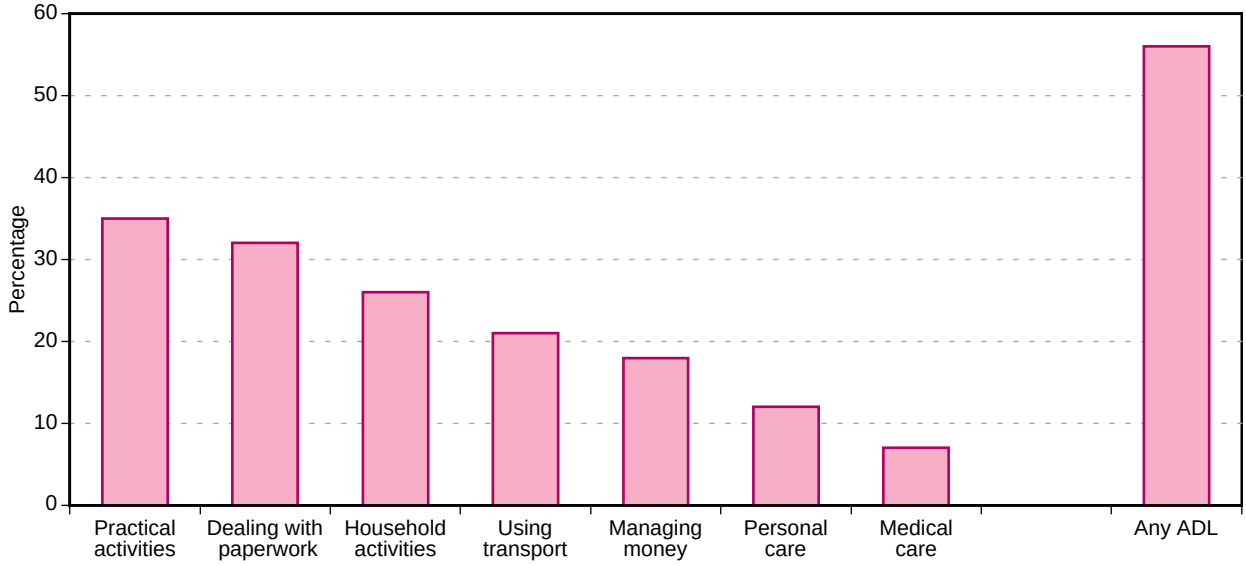
This chapter first considers which characteristics of this sample of people with a psychotic illness were associated with having difficulties with each activity of daily living. The extent to which the same people reported problems with more than one activity is then considered together with the factors associated with having four or more difficulties. Finally, section 3.4 looks briefly at the extent to which informants who needed help with activities received it and whether help was provided by health professionals or voluntary workers.

3.2 Difficulties with activities of daily living

Over half of this sample of people with psychotic disorder (56%) reported difficulties with activities of daily living (ADL) in one or more of the areas listed above. Most of these (49% of the whole sample) said that they needed help to overcome at least one of these difficulties. People were most likely to have difficulty with practical activities (35%), dealing with paperwork (32%) and household activities (26%) and least likely to report having difficulty with medical care (7%) or personal care (12%). *(Table 3.1 and Figure 3.1)*

Overall, there were no significant differences between men and women or between older and younger adults in the likelihood of reporting difficulties with activities of daily living. *(Table 3.2)*

Figure 3.1 Proportion of the sample having difficulty with different activities of daily living



Factors which were independently associated with difficulties with different aspects of daily living were examined using logistic regression, and the results are shown in Table 3.3. Respondents with high levels of neurotic symptoms (those with CIS-R scores of twelve or more) had significantly increased odds of having difficulties with all aspects of ADL, except for practical activities. Those who were economically inactive had increased odds of having difficulties with using transport, managing money, household activities and practical activities, but not personal care, medical care or dealing with paperwork. Compared with those who were employed in non-manual occupations, those from manual occupations had lower odds of having difficulty with household activities. It might be expected that those who had long standing physical complaints would have difficulties with a number of activities of daily living. However, this analysis shows that having a long standing physical complaint was independently associated only with difficulties with personal care and practical activities. Not surprisingly, the level of educational qualifications obtained was strongly associated with the need for help with paperwork – people with qualifications at A level or above had lower odds of having difficulties dealing with paperwork than those with lower levels of qualifications. *(Table 3.3)*

3.3 Number of difficulties experienced

Among this sample of adults with a psychotic illness, over a third (39%) had difficulties with two or more of the specified activities, and just under a sixth (15%) had difficulties with four or more of the activities. *(Table 3.4)*

Only three characteristics were independently associated with having difficulties with four or more ADLs. Single people had significantly lower odds of having difficulties with four or more ADLs than others (OR 0.16). Those with CIS-R scores of twelve and over both had significantly increased odds of having difficulties with four or more ADLs. Having a CIS-R score of 12 or more increased these odds nearly nine-fold (OR 8.92). *(Table 3.5)*

3.4 Help with activities of daily living

While people may find difficulty with ADLs, if these difficulties are not too great they may be able to manage without help. Further questions were therefore asked to identify how many people had difficulties severe enough to require help to overcome them, and from what sources they obtained this help. Overall, almost half of this sample of people with psychotic disorder (49%) reported that they needed help with one or more of the specified activities of daily living. There were no significant differences in the proportions of people reporting they needed help with any activities between men and women and older and younger people in this sample. *(Table 3.6)*

The majority of those who needed help with one or more activities were receiving help with at least one of the activities for which they needed it. However, of those who needed help, 4% received none for any activity of daily living for which they needed it and 11% had at least one difficulty for which they had an unmet need for help.

Table 3.7 shows that, family and friends were the most common providers of help for activities of daily living. Forty one per cent of those needing help received it from their spouse or partner, 36% from another relative and in 32% of cases, help was provided by a friend. Health or social care workers provided help for 19% of informants who needed help, while nearly a quarter of those needing help (23%) received help from others including, for example, paid domestic help and solicitors. *(Table 3.7)*

Table 3.1 Difficulties with activities of daily living

	Has difficulty with the activity	Needs help with the activity
	Percentage reporting each problem	
Has difficulty with...		
practical activities	35	30
dealing with paperwork	32	27
household activities	26	22
using transport	21	16
managing money	18	16
personal care	12	7
medical care	7	6
Any of the above	**56**	**49**
Base	*197*	*197*

Table 3.2 Difficulties with activities of daily living by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
			Percentage with each difficulty		
Has difficulty with...					
practical activities	32	38	28	40	35
dealing with paperwork	35	29	34	31	32
household activities	24	28	24	27	26
using transport	21	21	19	22	21
managing money	21	16	24	15	18
personal care	10	14	8	15	12
medical care	6	8	9	6	7
Any of the above	**59**	**52**	**52**	**58**	**56**
Base	*96*	*101*	*80*	*117*	*197*

Table 3.3 Odds ratios for characteristics associated with difficulties with different activities of daily living

	Personal care	Using transport	Medical care	Managing money	Household activities	Practical activities	Dealing with paperwork
				Adjusted odds ratios			
Social class							
Non-manual					1.00		
Manual					0.40*		
Employment status							
Economically active		1.00		1.00	1.00	1.00	
Economically inactive		4.05*		16.31**	6.19**	2.70**	
Educational qualifications							
A level and over							1.00
Other qualifications							4.92**
No qualifications							6.73***
CIS-R score							
Below 12	1.00	1.00	1.00	1.00	1.00		1.00
12 and over	4.12**	5.40***	17.89**	4.89***	6.61***		2.70**
Long standing physical complaints							
Absent	1.00					1.00	
Present	3.16*					2.02*	

*p<0.05; **p<0.01; ***p<0.001

Marital status, age, sex, tenure, household size and sample group were also included in the regression analyses but were not significant for any of the dependent variables

Table 3.4 Number of activities of daily living respondent had difficulties with by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Number of ADLs					
None	41	48	48	42	44
One	21	13	16	17	17
Two	14	17	14	16	15
Three	9	9	10	9	9
Four or more	16	14	12	16	15
Base	*96*	*101*	*80*	*117*	*197*

Table 3.5 Odds ratios for characteristics associated with difficulties with 4 or more ADL

	Has difficulty with 4 or more ADLs
	Adjusted odds ratios
Marital status	
Married	1.00
Single	0.16*
Widowed/divorced/separated	1.12
Employment status	
Economically active	1.00
Economically inactive	4.76
CIS-R Score	
Under 12	1.00
12 and over	8.92***

*p<0.05; **p<0.01; ***p<0.001

Table 3.6 Need for help with activities of daily living by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	Percentage needing help				
Needs help with...					
practical activities	27	34	25	34	30
dealing with paperwork	30	25	34	23	27
household activities	21	24	22	22	22
managing money	18	14	20	13	16
using transport	19	14	16	16	16
personal care	4	10	4	9	7
medical care	3	8	6	5	6
Any of the above	**51**	**48**	**50**	**49**	**49**
Base	*96*	*101*	*80*	*117*	*197*

Table 3.7 Sources of help with activities of daily living by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	Percentage receiving help from each source				
Help provided by...					
Spouse/cohabitee	35	48	32	47	41
Other relative	35	38	40	33	36
Friend	37	27	28	35	32
Health or social care worker	24	12	25	14	19
Other	22	23	15	28	23
Does not receive help for at least one difficulty for which help is needed	**8**	**15**	**12**	**11**	**11**
Does not receive help for any of the difficulties for which help is needed	**2**	**6**	**8**	**2**	**4**
Base (all needing help)	*49*	*48*	*40*	*57*	*97*

4 Economic activity and finances

4.1 Introduction

This chapter examines variation in economic activity and income among this sample of people with psychotic illness. It looks at characteristics associated with categories of economic activity – working full time, working part time, unemployed or economically inactive. It considers the circumstances of people in these categories and the extent to which mental health problems may have influenced their economic activity and financial position.

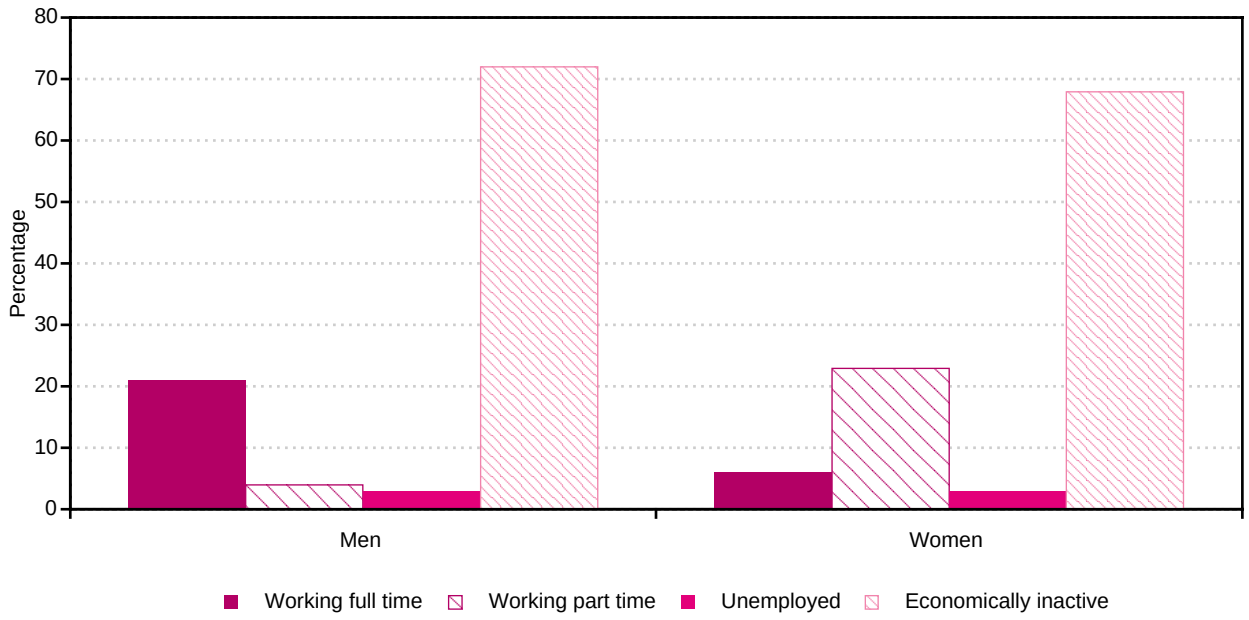
4.2 Economic activity and employment

Numerous studies have shown that being unemployed and economically inactive (i.e. unemployed and not seeking work) is associated with an increased risk of mental health problems (Fryers *et al*, 2002). In the report by Meltzer *et al* (2002) *The social and economic circumstances of adults with mental disorders* based on the main survey of psychiatric morbidity among adults in 2000, it was clear that, despite the small number in the sample with psychotic disorder, they were particularly likely to be unemployed or economically inactive.

In the population as a whole in the spring quarter of 2000, 60% of people aged 16 and over were in employment, 4% were unemployed and 36% were economically inactive (Office for National Statistics, 2002). In this sample of people with a psychotic disorder, a markedly higher proportion of people, 70%, were economically inactive. Just over a quarter (27%) were in paid employment, half of them full time and half part time. There was no association between levels of economic activity and age, with the under 45s as likely to be economically inactive as those over 45. There was also no difference between the sexes in the proportion of economically inactive respondents. However, among men, 21% worked in full time employment and 4% in part time employment, whereas among women, 6% worked in full time employment and 23% in part time employment. *(Table 4.1 and Figure 4.1)*

The majority (62%) of those who were economically inactive were not seeking work because they were long-term sick or disabled (62%), a fifth (20%) were retired and 12% were looking after their family or home. Just over four-fifths (81%) of economically inactive men said they were long-term sick or disabled, compared with

Figure 4.1 Economic activity status by sex



less than half (43%) of the women. Women were more likely to say they were looking after the family or home than men, 20% compared with 4%. There were also differences between the younger and older age groups. Nearly four-fifths (79%) of those under 45 said they were long-term sick or disabled, compared to half (51%) of those over 45. A third of those aged 45 and over (34%) said that they were retired. *(Table 4.2)*

Table 4.3 shows the results of logistic regression analyses to identify factors associated with economic activity in this group of people with psychotic disorder. Four variables were found to be independently associated with being in paid work. The strongest associations were with marital status and tenure; the odds of being in work if a person was widowed, divorced or separated were a quarter of those for people who were married, and those for people living in rented accommodation were a third those of owner occupiers. There were also significant associations with social class and CIS-R score. Those from a manual social class and those with CIS-R scores of 12 and over also had lower odds of being in work compared with those in a non-manual social class and those with lower levels of neurotic symptoms.

There was a very strong association between being economically inactive and tenure; those living in rented accommodation had an odds ratio more than 4 times higher than owner-occupiers. The level of neurotic symptoms was also independently associated, those with CIS-R scores of 12 and over were more likely to be economically inactive than those with lower scores.

Four variables were found to be independently associated with being unable to work due to long term illness or disability. The strongest association was with CIS-R score, having a high CIS-R score more than quadrupled the odds of not being able to work due to illness or disability. Living in rented accommodation trebled the odds while being male and living alone both independently increased the odds. *(Table 4.3)*

As well as asking about current employment status, the survey included specific questions about the extent to which mental health problems had directly affected the respondent's employment status and ability to do work. Among the adults in our sample who were in paid employment at the time of interview, almost half (47%) said that they had taken time off in the past year because of their health or the way they were feeling. The median number of days taken off (including time taken off for physical illness) was 14 days, while the mean was 70 days because of a small number of people having 5 months or more off because of ill-health. *(Table 4.4)*

Among those who were not currently working but had previously had a job, the majority, 59%, said this was because the way they had been feeling made it impossible for them to do any kind of job. Eighteen per cent were not working because of a physical health problem, 5% had been unable to find a suitable job and 12% said they did not want or need a job. Five per cent gave other reasons. Excluding those who did not wish to work, two-thirds (67%) of those not currently working felt that it would be impossible for them to do work, but just over a fifth (23%) felt that they could do sheltered work and one in six (17%) that they could do a part time job. *(Table 4.5)*

4.3 Finances

Survey respondents were asked some questions about their finances – about receipt of state benefits, income from other sources, their gross income and financial difficulties they had experienced.

4.3.1 State Benefits and income

Overall, at the time of interview 79% of respondents were receiving some form of state benefit or allowance. Receipt of particular allowances is shown in Table 4.6.

Twenty-eight per cent of informants were in receipt of one or more income-related benefits (income support, family credit or working families tax credit). The proportion was much higher among those aged under 45 (45%) than among those aged 45 and over (16%). *(Table 4.7)*

Over a half of informants, 52%, were in receipt of a benefit relating to a disability, i.e. Incapacity Benefit, Disability Living Allowance, Severe Disablement Allowance, Invalid Care Allowance, Disability Working Allowance, Attendance

Allowance, Statutory Sick Pay or Industrial Injury Disablement Benefit. Among men, this proportion was 66%, compared with 38% among women. *(Table 4.7)*

Table 4.8 shows the results of logistic regression analysis on receipt of benefits related to disability. Four variables were independently associated with receipt of benefits related to disability; sex, tenure, CIS-R score and whether the person lives alone. Men, those renting their accommodation, those with CIS-R scores of 12 and over and those living alone had increased odds of being in receipt of benefits related to a disability. As might be expected, these are the same factors that were found to be associated with being economically inactive due to being long-tem sick and disabled. *(Table 4.8)*

Apart from these benefits, over half of the sample (54%) had no other sources of income, and three respondents (2%) said they had neither state benefits nor other sources of income. Nearly a quarter (24%) of respondents had some earned income, including 8% of those who received benefits. Overall 14% had a pension from a former employer. *(Table 4.9)*

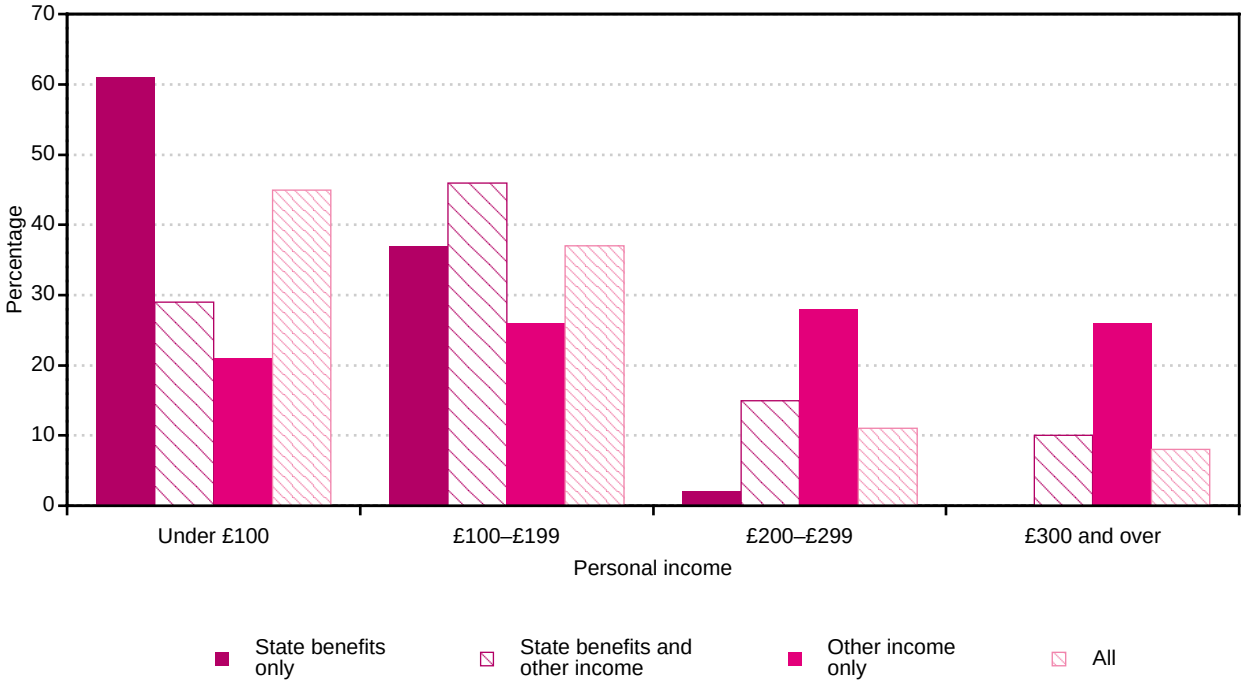
Almost half of this sample (45%) had a gross weekly income of under £100. For those on state benefits and without other sources of income, this rose to 61%, compared with 29% for those in receipt of state benefits but who had other sources of income, and 21% of those with other income and no state benefits. Only 2% of respondents on state benefits alone had gross weekly incomes of £200 or greater, compared with 25% of those on state benefits and with other sources of income, and 54% of those whose entire income came from other sources. *(Table 4.10 and Figure 4.2)*

4.3.2 Financial difficulties

Informants where asked whether, in the past 12 months, there had been times when they had been seriously behind in paying within the time allowed for a range of items.[1] Seventeen per cent answered that they had been. Among respondents with income other than state benefits, 6% had been in debt in the previous twelve months, whilst amongst those whose only source of income was state benefits, or who had no source of income, over a quarter (27%) had experienced debt in the twelve months before interview. *(Table 4.11)*

Almost a tenth (9%) of this sample had been disconnected from one or more of the utilities (water, gas, electricity, telephone) in the previous twelve months. The rate was higher (14%) among those whose only source of income was from state benefits than among those with other sources of

Figure 4.2 Level of income by source of income



income (2%). Eighteen per cent of the sample reported using less of at least one of these utilities because they were unable to afford it. Among those on benefits alone, over a quarter (29%) had used less than they needed, compared with 7% of those with income from other sources. *(Table 4.12)*

Finally, informants were asked whether there had been times during the past year when they had borrowed money from pawnbrokers, money-lenders, friends or relations in order to pay for their day-to-day needs. A fifth (20%) said that they had. Most often this was from family (11%) and friends (10%), but 4% had borrowed money from a money-lender and 1% from a pawnbroker. Borrowing for day-to-day needs was higher among those with no income other than benefits, of whom 30% had borrowed money, compared with 10% of those with other sources of income. *(Table 4.13)*

Note

1 Items asked about were rent, gas, electricity, water, hire purchase repayments, mortgage repayments, council tax, credit card repayments, mail order catalogue repayments, telephone, TV licence, road tax, DSS Social Fund loan, and other loan repayments.

Table 4.1 Employment status

by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Employment status					
Working full time	21	6	11	15	13
Working part time	4	23	14	14	14
Unemployed	3	3	5	2	3
Economically inactive	72	68	70	70	70
Base	*96*	*101*	*80*	*117*	*197*

Table 4.2 Reason for economic inactivity

by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Reason for not seeking work					
Long-term sick or disabled	81	43	79	51	62
Retired from paid work	13	28	-	34	20
Looking after the family/home	4	20	16	10	12
Student	1	1	2	1	1
Temporarily sick or injured	-	3	2	1	1
Other	-	4	2	2	2
Base = economically inactive	*69*	*69*	*56*	*82*	*138*

Table 4.3 Odds ratios for characteristics associated with economic activity†

	Working	Economically inactive	Not working as sick or disabled
	Adjusted odds ratios		
Sex			
Female			1.00
Male			2.50*
Marital status			
Married/cohabitting	1.00		
Single	0.51		
Widowed/divorced/separated	0.23**		
Household size			
Lives with others			1.00
Lives alone			2.43*
Social class			
Non-manual	1.00		
Manual/not known	0.44*		
Tenure			
Owner	1.00	1.00	1.00
Renter	0.32**	4.44***	3.15**
CIS-R score			
Below 12	1.00	1.00	1.00
12 and over	0.40*	2.11*	4.68***
Other factors entered in the model but not significantly associated with any dependent variable	Age, educational qualifications, source of sample, long-standing physical illness		

*p<0.05; **p<0.01; ***p<0.001
† The number of people classified as unemployed was too small to allow analysis.

Table 4.4 Time off work in the past year due to ill-health

	%
Had time off work...	
Yes	47
No	53
*Base**	*58*
Median number of days off**	**14**
Mean number. of days off**	**70**

* People who had worked in past year.
** People who had taken time off for ill-health only.

Table 4.5 Reason for not currently working and type of employment possible for those who have previously had a job

	%
Reason not currently working	
Way they feel makes it impossible	59
Physical health problem	18
Unable to find suitable job	5
Do not want or need a job	12
Other reasons	5
Base	*116*
	Percentage giving each answer
Type of employment possible	
Could do sheltered work	23
Could do part-time work	17
Impossible to do work	67
*Base**	*96*

* Those who wanted/needed work only.

Table 4.6 State Benefits received

	% receiving benefit
Benefit	
Disability-related benefits	
Incapacity Benefit	31
Care component of Disability Living Allowance	14
Disability Living Allowance nes	14
Mobility Allowance of Disability Living Allowance	12
Severe Disablement Allowance	9
Attendance Allowance	2
Industrial Injury Disablement Benefit	2
Invalid Care Allowance	2
Disability Working Allowance	1
Statutory Sick pay	1
Any disability related benefit	**52**
Income-related benefits	
Income Support	27
Family Credit/Working Families Tax Credit	2
Any income-related benefits	**28**
Other benefits	
Retirement Pension	16
Child Benefit	11
One Parent Benefit	2
Widows Pension or Allowance	1
Jobseekers Allowance	1
Any other benefits	**30**
Householder receiving Housing Benefit	38
Any benefit received	**79**
No benefits received	**21**
Base	*196*

Table 4.7 Benefits received by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
			% receiving benefit		
Benefit received					
Benefit related to a disability	66	38	56	48	52
Householder receiving Housing benefit	48	30	49	31	38
Other benefit	12	46	25	32	30
Income-related benefit	33	22	45	16	28
Any benefit	**80**	**77**	**80**	**78**	**79**
Base	*97*	*103*	*80*	*120*	*200*

Table 4.8 Odds ratios for characteristics associated with receipt of benefits related to a disability

	Receiving benefit related to a disability
	Adjusted odds ratios
Sex	
Female	1.00
Male	2.99**
Household size	
Lives with others	1.00
Lives alone	2.46*
Tenure	
Owned	1.00
Rented	2.39*
CIS-R score	
Below 12	1.00
12 and over	3.54***
Other factors entered in the model but not significantly associated with the dependent variable	Age, marital status, social class, educational qualifications, source of sample, physical complaint

*p<0.05; **p<0.01; ***p<0.001

Table 4.9 Sources of income other than benefits by whether or not benefits were received

	Receiving state benefits		
	Yes	No	All
	Percentage with income from each source		
Source of income			
Earnings from employment	8	81	24
Interest from savings	16	36	20
Pension from former employer	15	10	14
Other income	8	5	8
None of these	66	7	54
Base	*154*	*42*	*196*

Table 4.10 Income

by source of income

	Source of income			
	State benefits only	State benefits and other income	Other income only	All*
	%	%	%	%
Level of income				
Under £100	61	29	21	45
£100–£199	37	46	26	37
£200–£299	2	15	28	11
£300 and over	-	10	26	8
Base	*100*	*52*	*39*	*194*

* 3 respondents who said they had no income are included in 'All'.

Table 4.11 Financial debts

by source of income

	Income source		
	State benefits only or no income	Other income source	All
	Percentage experiencing each problem		
Respondent has been behind in payments for...			
Water	8	1	5
Telephone	9	1	5
Rent	7	0	4
Council Tax	6	2	4
Mail order catalogue	5	2	4
TV licence	6	1	4
Gas	5	0	3
Electricity	4	0	2
Other loans	3	1	2
Goods on hire purchase	1	1	1
Mortgage repayments	2	0	1
Credit Card payments	0	1	1
Road Tax	0	1	1
DSS Social Fund Loan	1	0	1
None of these	73	94	83
Base	*105*	*91*	*196*

Table 4.12 Financial difficulties

by source of income

	Source of income		
	State benefits only or no incoe	Other income source	All
	Percentage experiencing each problem		
Respondent has been disconnected from...			
Telephone	11	1	7
Electricity supply	3	0	2
Water supply	2	0	1
Gas supply	1	1	1
Any of these	**14**	**2**	**9**
Respondent has used less...			
Electricity supply	15	5	11
Gas supply	15	3	10
Telephone	13	2	8
Water supply	2	0	1
Any of these	**29**	**7**	**18**
Respondent has borrowed from...			
Family	16	5	11
Friend(s)	14	4	10
Moneylender	7	1	4
Pawnbroker	1	0	1
Any of these	**30**	**10**	**20**
Base	*105*	*91*	*196*

5 Social networks and perceived social support

5.1 Introduction

The psychiatric morbidity surveys examined two aspects of social functioning:

- extent of social networks; and
- self perceived social support.

This chapter considers each of these aspects of social functioning within this sample of people with a psychotic illness.

5.2 Extent of social networks

Information on social networks was obtained through questions about the numbers of friends and relatives informants felt close to:

- adults who lived with respondents and to whom they felt close;
- relatives living elsewhere to whom they felt close; and
- friends or acquaintances living elsewhere who informants would describe as close or good friends.

People in the three categories above were defined as the respondent's 'primary support group'. These questions were used in earlier surveys of psychiatric morbidity carried out by ONS including the 2000 survey of psychiatric morbidity among adults living in private households. Research suggests that adults whose total primary support group numbers three or fewer adults are at greatest risk of psychiatric illness. (Brugha *et al*, 1987; Brugha *et al*, 1993)

For the purposes of this report, the people were grouped into three categories based on the size of their primary support group: 0–3, 4–8 and 9 and over. In the survey of adults living in private households in 2000 only 5% had a small primary support group (less than four people) but the small group of people with probable psychotic disorder stood out as the group most likely to have a small primary support group (Meltzer *et al*, 2002b). Among the sample of people with a psychotic illness covered in the current report (which includes people from that general household survey), a fifth (20%) reported feeling close to fewer than four people, while just over two-fifths (42%) had a primary support group of between four and eight people and 39% had nine or more people to whom they felt close or described as good friends.

There were no differences between men and women in the size of their primary support groups. People aged 45 and over, however, were more likely than those aged under 45 to have primary support groups of 9 people or more, 46% compared with 29%. *(Table 5.1)*

5.3 Perceived social support

Perceived social support was derived from respondents answers to seven questions originally fielded in the 1987 Health and Lifestyle survey (Breeze *et al*, 1994) and also included in other ONS surveys of psychiatric morbidity. The seven questions take the form of statements that individuals could say were not true, partly true or certainly true for them:

There are people I know – amongst my family or friends:

- who do things to make me happy;
- who make me feel loved;
- who can be relied upon no matter what happens;
- who would see that I am taken care of if I needed to be;
- who accept me just as I am;
- who make me feel an important part of their lives; and
- who give me support and encouragement.

Responses to each statement were scored 1 for not true, 2 for partly true and 3 for certainly true. Overall scores, therefore, could range from 7, if all answers were not true, to 21 if all answers were certainly true. The scores were categorised into three groups, following the conventions used in earlier surveys in this series:

- score of 21 – no lack of social support;
- score of 18–20 – moderate lack of social support; and
- score of 17 or less – severe lack of social support.

Just over one-fifth (21%) of this sample of people with psychotic illnesses were classified as having a severe lack of perceived social support, while 25% had a moderate lack and 54% had no lack of social support.

Sex and age were both associated significantly with having a severe lack of social support. Twenty-nine per cent of men, compared with 15% of women, were classified as having a severe lack of social support, as were 31% of people aged under 45 compared with 14% of those aged 45 and over. *(Table 5.2)*

Figure 5.1 illustrates that a clear relationship exists between the size of an informant's primary support group and perceived social support. The proportion of respondents with a perceived severe lack of social support was only 8% among those with primary support groups of nine or more people, rising to 24% of those with primary support groups of between 4 and 8, and 41% among those with a small primary support group of 3 or fewer people. *(Figure 5.1 and Table 5.3)*

Table 5.4 shows the results from multiple logistic regression to identify factors independently associated with perceived social support levels and size of primary support group. The odds of perceiving a severe lack of social support were lower for women than for men, and for those aged 45 and over than for those under 45. Informants who were single, widowed or divorced had odds more than double those of married informants of perceiving a severe lack of social support. Those with CIS-R scores of twelve or more were more likely than those with scores below 12 to perceive a severe lack of social support.

The only characteristic independently associated with having a primary support group of three or fewer people was CIS-R score – those with scores of 12 or more had odds four and a half times greater than those with lower scores of having a support group of three or fewer people. *(Table 5.4)*

Fig 5.1 Perceived social support by size of primary support group

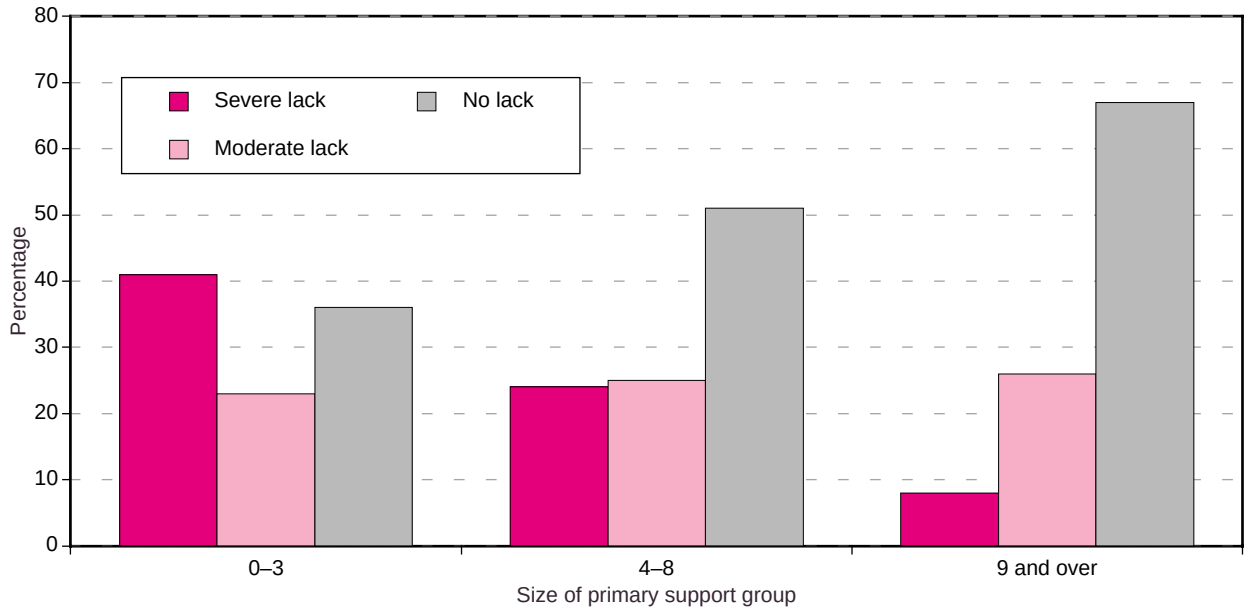


Table 5.1 Size of primary support group
by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Size of primary support group					
0–3	20	19	28	14	20
4–8	41	42	44	40	42
9 and over	39	39	29	46	39
Base	*97*	*103*	*80*	*120*	*200*

Table 5.2 Perceived social support
by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Perceived social support					
Severe lack of support	28	15	31	14	21
Moderate lack of support	24	26	24	26	25
No lack of support	48	59	45	60	54
Base	*97*	*103*	*80*	*120*	*200*

Table 5.3 Peceived social support
by size of primary support group

	Size of primary support group			
	0–3	4–8	9 and over	All
	%	%	%	%
Perceived social support				
Severe lack of support	41	24	8	21
Moderate lack of support	23	25	26	25
No lack of support	36	51	67	54
Base	*39*	*83*	*78*	*200*

Table 5.4 Odds ratios for characteristics associated with severe lack of social support and primary support group of fewer than 3 people

	Has severe lack of social support	Has primary support group of three or fewer people
	Adjusted odds ratios	
Sex		
Male	1.00	
Female	*0.46	
Age group		
Under 45	1.00	
45 and over	*0.42	
Marital status		
Married	1.00	
Single, widowed, divorced	*2.23	
CIS-R score		
Below 12	1.00	1.00
12 and over	*2.52	***4.63

*p<0.05; **p<0.01; ***p<0.001

Other variables not significantly associated: Social class, tenure, physical complaint, educational qualifications, household size, source of sample.

6 Tobacco, alcohol and drugs

6.1 Introduction

Measures of cigarette smoking, alcohol use and drug misuse were collected for all respondents. Everyone was asked a series of questions about their use of tobacco, alcohol and illegal drugs. Those who drank alcohol or used drugs such as cannabis, heroin or cocaine were asked further questions to assess their consumption and possible dependence. Computer-Assisted Self-Interviewing (CASI), in which respondents enter their own answers into the computer, was used for the sections on alcohol dependence and drug use to encourage honest answers to these potentially sensitive questions. This chapter first describes levels of smoking, then the extent of hazardous drinking and alcohol dependence, before examining drug dependence.

6.2 Cigarette smoking

Informants were asked whether they had ever smoked cigarettes, and if so, whether they smoked nowadays. Smokers were asked how many cigarettes a day they smoked separately for weekdays and weekends. Daily consumption was computed as a mean of these figures. For analysis, adults were grouped into the following classifications:

- those who never have been a regular smoker;
- ex-smokers;
- those currently smoking below 10 cigarettes daily;
- those currently smoking 10 or more a day but fewer than 20; and
- those currently smoking 20 or more cigarettes a day.

A large proportion of adults in this sample of people with a psychotic illness were, or had been, smokers: 44% were smokers, a fifth (20%) were ex-smokers and just over a third (36%) had never been a regular smoker. In comparison, the 2000 General Household Survey found that amongst the general population aged 16 to 74 years 29% smoked, 22% were ex-smokers and half (50%) had never smoked. As well as having a high prevalence of smoking, a large proportion of people with psychotic illness reported smoking heavily (i.e. 20 or more cigarettes a day). Just over a quarter (27%) of the sample of people with psychotic illness were heavy smokers while only one in twelve (9%) of the general population in the same age group smoked heavily.

In this sample, as in the general population, women were generally less likely to smoke than men and also smoked less. For example, 43% of women had never smoked compared with 27% of men. Conversely almost a third (32%) of men were heavy smokers (smoking 20 or more cigarettes a day) compared with just under a quarter (24%) of women. The proportions of people under and over 45 years old who had never smoked were similar, however over a quarter (28%) of those aged 45 and over were ex-smokers compared to only 9% of those aged under 45. *(Table 6.1)*

Logistic regression analysis was carried out to establish which characteristics were independently associated with cigarette smoking and with heavy cigarette smoking (20 or more cigarettes daily) in this sample of people with a psychotic disorder. The analysis showed that age group and tenure were associated with both smoking and heavy smoking. For those in the youngest age group (16 to 34) the odds of being a smoker were five times those for the oldest age group (55 to 74) and the odds of being a heavy smoker were more than four times higher. Those aged 35 to 44 and 45 to 54 were also more likely to smoke than those aged 55 to 74. Those who rented their home had odds of being a smoker two and a half times greater than those who owned their home, and three times greater of being heavy smokers. High CIS-R scores were also independently associated with being a heavy smoker. The odds of being a heavy smoker were three times higher for those with CIS-R scores of 12 and over than for those with lower CIS-R scores. *(Table 6.2)*

6.3 Alcohol consumption

Two instruments were used to assess alcohol misuse – the Alcohol Use Disorders Identification Test (AUDIT) and the Severity of Alcohol Dependence questionnaire (SAD-Q). The AUDIT was developed from a six-country WHO collaborative project and has been shown to be a good indicator of hazardous alcohol use (Saunders *et al,* 1993). It defines hazardous drinking as an established pattern of drinking, which brings the risk of physical and psychological harm now or in the future. The year before interview is used as a reference period. Answers to all questions are scored from 0 to 4 and then summed to provide a total score ranging from 0 to 40. A total score of 8 and over is the threshold used to provide an assessment of hazardous drinking.

The prevalence of alcohol dependence in the six months before interview was assessed using the Severity of Alcohol Dependence questionnaire (SAD-Q) (Stockwell *et al*, 1983). The SAD-Q was asked of all respondents who had an AUDIT score of 10 and over. A total SAD-Q score of 3 or less indicates no dependence, while a score of four or above suggests some alcohol dependence. Mild dependence is indicated by a score of between 4 and 19, moderate dependence by a score of 20–34, and severe dependence by a SAD-Q score of 35–60.

For the current analysis we have used a classification based on both measures. The categories are:

- No hazardous drinking – those with an AUDIT score of less than 8.
- Hazardous level of drinking but no dependence – those with an AUDIT score of 8 or more, but a SAD-Q score of between 0 and 3.
- Alcohol dependence – those with an AUDIT score of 8 or more and a SAD-Q score of 4 or more.

Among this sample, 27% of respondents had an AUDIT score of 8 or more – that is, they were found to have a hazardous level of drinking in the year before interview. This is a similar level of hazardous drinking to that found in the household sample, at 25% (Singleton *et al*, 2001). Thirteen per cent were found to have hazardous levels of drinking without alcohol dependence, and 14% were classified as alcohol dependent. Men and women showed different patterns of alcohol consumption. Among men, 37% were drinking alcohol at hazardous levels, and 21% showed evidence of alcohol dependence. Among women, 18% had hazardous levels of alcohol consumption, while 8% were alcohol dependent. In the general population younger people tend to drink more heavily than older adults and the same was true in this sample: those aged under 45 years were twice as likely as those aged 45 and over to show signs of alcohol dependence – 22% compared with 9%. *(Table 6.3)*

Logistic regression analysis was carried out to establish characteristics independently associated with alcohol dependence in this sample of people with a psychotic illness. Those with CIS-R scores of twelve and over had odds of being alcohol dependent over five times greater than those without evidence of neurotic illness. Women and informants with a long standing physical complaint both had significantly lower odds than men and those with no long standing physical complaint of being alcohol dependent. *(Table 6.4)*

6.4 Illicit drug use

Informants were asked about their illicit use of drugs, including sedatives, tranquillisers, cannabis, amphetamines, cocaine, heroin, hallucinogens, ecstasy and solvents. Illicit use of drugs was established by presenting informants with a list of drugs and asking them whether they had used any of the drugs without a prescription from the doctor. Overall, 30% reported ever using one or more of the specified drugs, and 8% reported having done so within the last 12 months. These levels are similar to those found in the household survey. *(Table 6.5)*

Further information about drug use in the year preceding interview was collected about six drugs: cannabis, amphetamines, crack, cocaine, ecstasy, tranquillisers and opiates. Included in the questions about drug use in the past year and month were five questions to measure drug dependence. The topics covered by these questions were:

- Frequency of drug use: used drug every day for two weeks or more.
- Stated dependence: felt they needed it or were dependent on it.
- Inability to cut down: tried to cut down but could not.
- Need for larger amounts: needed more to get an effect.
- Withdrawal symptoms: feeling sick because stopped or cut down.

A positive response to any of the five questions was used to indicate drug dependence. For the purposes of analysis informants were grouped into those who were dependent on cannabis only, those who were dependent on another drug (with or without associated dependence on cannabis), and those with no drug dependence. It should be noted that the threshold for dependence used here is quite low. People who are frequent users (i.e. daily users for a fortnight or more) or who have developed some tolerance for the drug, so require more to get the same affect, will be assessed as dependent. A large proportion of those assessed as dependent on cannabis and ecstasy had only scored one on the dependence questions. This threshold was used to provide comparability with the 1993 survey but may overestimate dependence on some drugs.

Among this sample, 1% were classified as dependent on cannabis, and 2% on drugs other than cannabis (with or without cannabis dependence). There were no statistically significant differences between men and women, or between age groups. *(Table 6.6)*

Table 6.1 Cigarette smoking by sex and age

	Sex		Age		All	General population (GHS 2000)*
	Male	Female	Under 45	45 and over		
	%	%	%	%	%	%
Daily cigarette consumption						
Never smoked	27	43	34	37	36	50
Ex-smoker	24	17	9	28	20	22
1–9 cigarettes per day	7	3	9	3	5	8
10–19 cigarettes per day	9	14	16	9	12	12
20 and over cigarettes per day	32	24	32	24	27	9
Base	*96*	*102*	*80*	*118*	*198*	*12814*

*Source: General Household Survey, 2000, Office for National Statistics, people aged 16 to 74 only

Table 6.2 Odds ratios for characteristics associated with smoking and heavy smoking

	Smoking	Heavy smoking
	Adjusted odds ratios	
Age group		
16–34	5.04**	4.36*
35–44	3.28**	1.36
45–54	3.50**	3.49*
55–74	1.00	1.00
Tenure		
Owns home	1.00	1.00
Rents home	2.60**	3.01**
CIS-R score		
Below 12		1.00
12 and over		2.98**
Other variables included in the models but not significant for either of the dependent variables:	Marital status, sex, household size, employment status, educational qualifications, social class, long-standing physical complaint and sample group	

*p<0.05; **p<0.01; ***p<0.001

Table 6.3 Level of alcohol consumption by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Level of alcohol consumption					
No hazardous drinking[1]	63	82	67	77	73
Hazardous drinking but no dependence[2]	16	10	11	14	13
Alcohol dependence[3]	21	8	22	9	14
Base	*96*	*102*	*80*	*118*	*198*

1 AUDIT score <8.
2 AUDIT score ≥8 but SAD-Q score 0–3.
3 AUDIT score ≥8 and SAD-Q score 4 and over.

Table 6.4 Odds ratios for characteristics associated with alcohol dependence

	Alcohol dependence
	Adjusted odds ratios
Sex	
Male	1.00
Female	0.32*
CIS-R score	
Below 12	1.00
12 and above	5.16***
Long standing physical complaint	
Absent	1.00
Present	0.29**
Other variables included in the regression model but not significant for the dependent variable	Marital status, age group, household size, employment status, educational qualifications, social class, tenure and sample group

*p<0.05; **p<0.01; ***p<0.001

Table 6.5 Illicit drug use

by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
			Percentage reporting use		
Illicit drug use					
Ever used an illicit drug	39	22	45	19	30
Used an illicit drug in last year	10	5	12	4	8
Base	*96*	*102*	*80*	*118*	*198*

Table 6.6 Drug dependence

by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	*%*	*%*	*%*	*%*
Drug dependence					
None	96	98	94	99	97
Dependent on cannabis only	2	-	1	1	1
Dependent on other drug with or without cannabis	2	2	5	-	2
Base	*96*	*102*	*80*	*118*	*198*

7 Stressful life events, suicidal thoughts and behaviours

7.1 Introduction

People with psychotic illness are known to be at particularly high risk of suicide (Westermeyer *et al*, 1991; Harris and Barraclough, 1998; Inskip *et al*, 1998; Department of Health, 2001). In this survey a series of questions was asked looking at suicidal thoughts and non-fatal suicidal behaviour as well as deliberate self-harm without suicidal intent. Four questions were included to assess self-harm with suicidal intent, based on the work of Paykel *et al* (1974) and Salmons and Harrington (1984).

1. Have you ever thought that life was not worth living?
   (If YES, in the last week, last year, or at another time)
2. Have you ever wished that you were dead?
   (If YES, in the last week, last year, or at another time)
3. Have you ever thought of taking your life, even though you would not actually do it?
   (If YES, in the last week, last year, or at another time)
4. Have you ever made an attempt to take your life, by taking an overdose of tablets or in some other way?
   (If YES, in the last week, last year, or at another time)

Responses to question 3 were used to assess suicidal thoughts and those to question 4 for non-fatal suicidal behaviour.

To measure deliberate self-harm without the intention of suicide, respondents were asked an additional question.

5. Have you deliberately harmed yourself in any way but not with the intention of killing yourself?

Respondents who answered yes to this question were then asked a series of questions about how they had harmed themselves and for what reasons. All information about non-fatal suicidal behaviour was obtained from these interviews. No records were assessed.

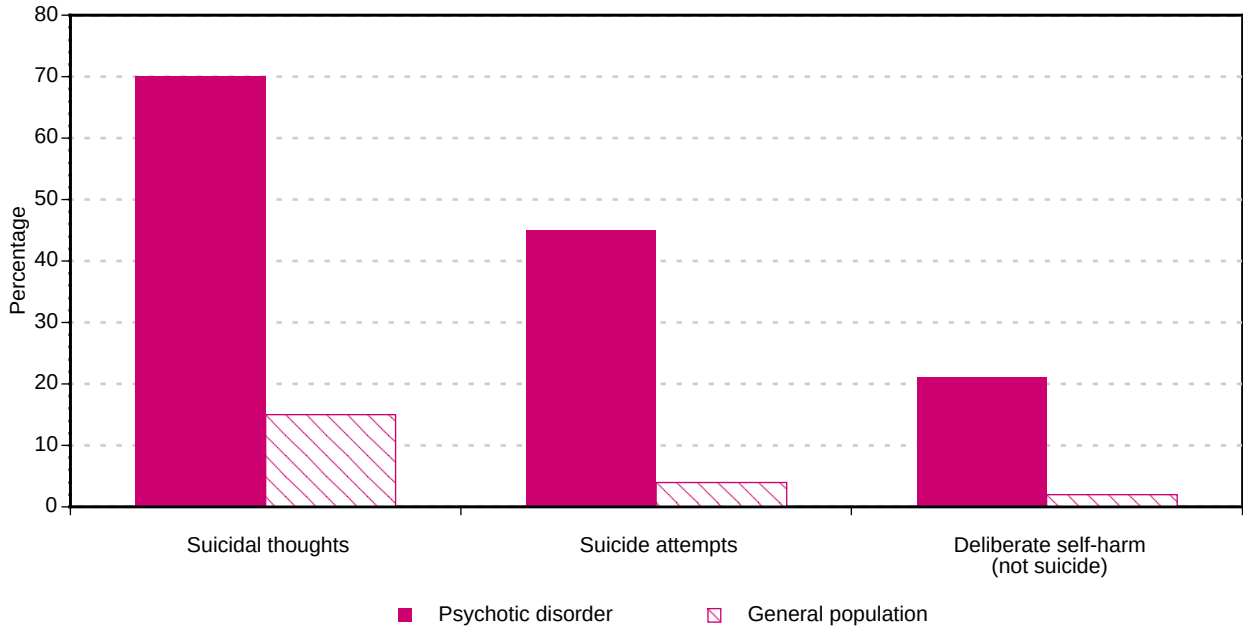
An earlier report, based only on the main survey of psychiatric morbidity among adults living in private households in 2000, considered factors associated with non-fatal suicidal thoughts and behaviours among the general population (Meltzer *et al*, 2002). This found the strongest correlates of non-fatal suicidal behaviour to be the number of stressful life events experienced, age, psychotic disorder, depression and mixed anxiety and depression and dependence on drugs other than cannabis. However, the number of people with psychotic disorder in the main survey sample was very small. This chapter looks at the prevalence of suicidal thoughts and self-harm with and without suicidal intent among the larger group of people with psychotic disorder covered by this report. It also considers the extent of stressful life events experienced by this group and the association between these and suicidal thoughts and behaviours.

7.2 Prevalence of suicidal thoughts and deliberate self-harm

Over two-thirds (70%) of this sample of people with a psychotic illness had had suicidal thoughts at some time in their lives and 45% had attempted suicide, while 21% had harmed themselves without intending to commit suicide. These rates are far higher than those found in the general household population aged 16 to 74, in which the corresponding figures were 13% reporting suicidal thoughts, 4% attempted suicide and 2% deliberate self-harm at sometime in their lives. *(Table 7.1 and Figure 7.1)*

In the general population women and younger people were more likely to report suicidal thoughts, and suicide attempts and other deliberate self-harm was also more common among younger people (Meltzer *et al*, 2002). However, in this group of people with a psychotic illness there was no difference between men and women in the prevalence of suicidal thoughts, nor for self-harm with or without suicidal intent. Younger people in the sample were more likely to report all of these behaviours than those aged 45 or over. *(Table 7.1)*

Figure 7.1 Lifetime prevalence of non-fatal suicidal behaviour: people with psychotic disorder compared with the general population



7.3 Stressful life events

Meltzer *et al* (2002) found a very strong relationship between the number of stressful life events a person had experienced and their likelihood of reporting suicidal thoughts and attempts and other types of self-harm. Everyone in our sample of people with psychotic disorders was asked the same series of questions about their experience of a range of stressful life events.

All respondents were shown three sets of cards that listed a range of stressful life events (18 in total) and were asked to say which, if any, they had suffered at any time of their life. They covered relationship problems, illness and bereavement; employment and financial crises; and victimisation experiences. All are events which might have an adverse effect on a person's mental health. They were also used in the ONS survey of psychiatric morbidity among prisoners (Singleton *et al*, 1998).

However, the lists did not include all common stressful events, excluding for example, moving house and having a baby. Previous research has shown that events such as these are unlikely to significantly increase risk for psychiatric disorders. (Brugha *et al*, 1985). In addition, when looking at the number of events experienced, it should be remembered that the events may not carry equal weight in terms of their psychological impact, and that some events are likely to be found in combination with others; for example running away from home and homelessness. If an event was reported in the lifetime of the individual, a further question established whether this was within the past six months.

The proportion of people reporting experiencing stressful life events was far higher in this sample of people with psychotic illness than in the general household population aged 16 to 74. Almost everyone in the sample (97%) had experienced one of the events in the group concerning relationship problems, illness and bereavement. Compared with the general household population, this sample reported experiencing particularly high rates of serious illness or assault to themselves, 63% compared with 26% in the general population, but this may reflect the fact that psychotic disorder would be classified as a severe illness by most people. Rates of divorce or separation were also much higher than in the general population, 47% compared with 22%. They were also more than twice as likely to report a serious problem with a close friend or relative, 30% did so compared with 12% of people in the main household survey. *(Table 7.2)*

Given the low rate of employment and the low incomes experienced by this group of people with a psychotic illness that are described in chapter 4 of

this report, it is not surprising that stressful events relating to employment and finances were also far more common in this sample than in the general household population. They were also much more likely to report having had a problem with the police involving a court appearance – 22% reporting having done so compared with only 9% in the general population. Men in the sample were more likely than women to report all of this group of stressful events, except having something they valued lost or stolen, but there were no differences between the age groups. *(Table 7.2)*

A very high proportion of people in this sample reported experiencing one of the types of victimisation covered in the survey. Over a fifth (21%) reported sexual abuse and the rate was significantly higher among women and younger people (31% in each case). About a quarter of the sample said they had experienced violence in the home (25%) and being homeless (23%), while 41% said they had suffered bullying. As well as reporting a higher rate of sexual abuse, younger people were more likely to report bullying, running away from home and being expelled from school. *(Table 7.2)*

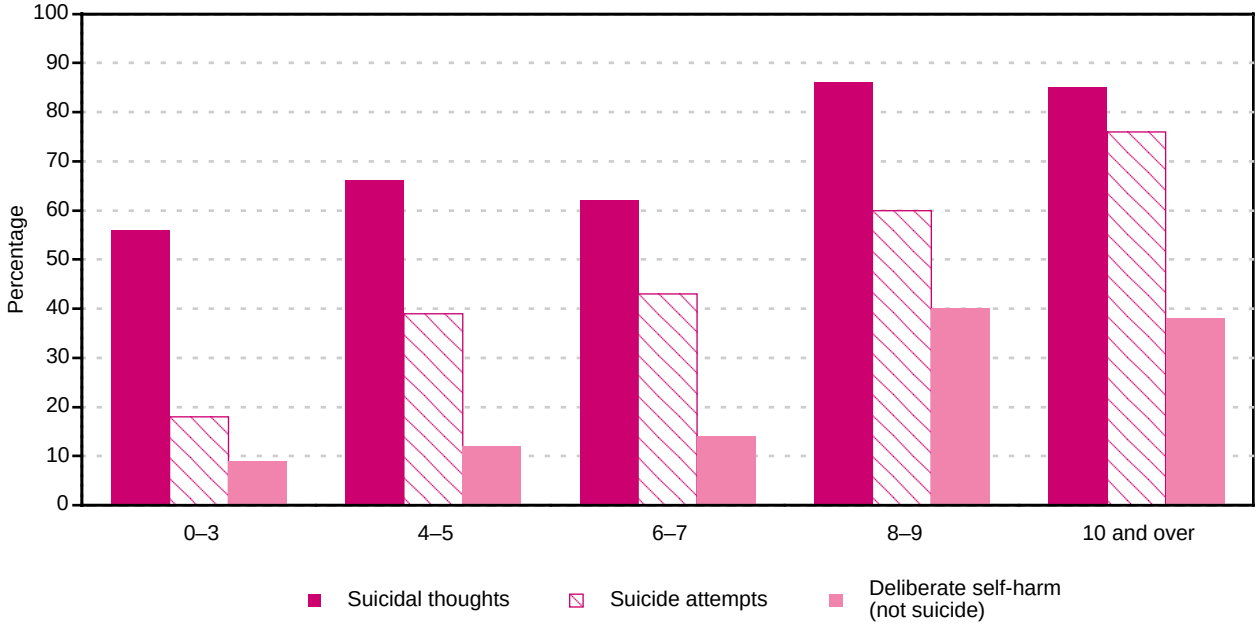
Meltzer *et al* (2002) found that the number of stressful life events was a more important predictor of suicidal thoughts and behaviours than the individual events experienced. In the survey of psychiatric morbidity among adults living in private households 17% of the sample reported 6 or more of the stressful events and this group had markedly increased odds of suicidal thoughts and self-harm with or without suicidal intent compared with people who had not experienced any of the events. In this sample of people with a psychotic illness over half, 57%, had experienced six or more events and 17% reported ten or more of them. *(Table 7.3)*

7.4 Factors associated with suicidal thoughts and behaviours

As was the case in the general household population (Meltzer *et al*, 2002), the proportion of people in this sample who reported suicidal thoughts and, in particular, self-harm with or without suicidal intent increased with the number of stressful life events they reported. Those who reported eight or more events had particularly high rates; over 80% reporting suicidal thoughts and over 60% attempting suicide at some time in their lives. *(Table 7.4, Figure 7.2)*

When the relationship between non-fatal suicidal behaviours and individual events are considered, a few events stand out as being associated with particularly high rates of suicide attempts at some time. Among those who reported a serious problem with a close friend or relative, 66% said they had attempted suicide at sometime in their life (compared with 44% of the sample as a whole). A similar proportion of those who had experienced violence in the home had attempted suicide (67%)

Figure 7.2 Lifetime prevalence of non-fatal suicidal behaviours by number of stressful life events



as had 71% of those who had been homeless and 74% of those who had experienced sexual abuse. (Tables 7.5 to 7.7)

Logistic regression analysis was carried out to identify those factors independently associated with non-fatal suicidal thoughts and behaviours in this sample of people with probable psychotic disorder. As well as the factors listed in chapter 1 and considered throughout this report in these analyses, the number of stressful life events was also included in the modelling procedures. The presence of significant levels of neurotic symptoms, as shown by a CIS-R score of 12 and over, was associated with a four-fold increase in the odds of reporting suicidal thoughts at some time in one's life. In contrast having a longstanding physical health problem was associated with a decreased likelihood of reporting suicidal thoughts once other factors had been taken into account. High levels of neurotic symptoms were also significantly associated with suicide attempts and in this case the number of stressful life events also showed a very strong association. The odds ratio for those reporting 10 or more stressful life events compared to those reporting 0 to 3 was 12.2. The two factors independently associated with deliberate self-harm without suicidal intent were the number of stressful life events and younger age. *(Table 7.8)*

Table 7.1 Prevalence of non-fatal suicidal behaviour by sex and age

	Sex		Age		All	Household population*
	Male	Female	Under 45	45 and over		
	Cumulative percentage of population					
Suicidal thoughts						
Past week	4	7	10	2	6	0
Past year	22	23	31	17	22	4
Lifetime	69	70	78	64	70	13
Never	31	30	22	36	30	87
Suicide attempts						
Past week	-	-	-	-	-	0
Past year	5	9	10	5	7	1
Lifetime	45	45	53	40	45	4
Never	55	55	47	60	55	96
Deliberate self-harm without suicidal intent	22	21	33	13	21	2
Base	*97*	*103*	*80*	*120*	*200*	*8572*

* Adults aged 16 to 74 living in private households (Meltzer *et al*, 2002; Table 3.1).

Table 7.2 Stressful life events by sex and age

	Sex		Age		All	General population*
	Male	Female	Under 45	45 and over		
	Percentage reporting experiencing each event					
Relationship problems, illness and bereavement						
Death of close friend/other relative	70	73	70	73	72	64
Death of close relative	76	77	51	94	77	54
Serious illness or assault	64	62	60	65	63	26
Serious illness or assault to close relative	24	38	32	30	31	24
Separation or divorce	41	52	46	47	47	22
Serious problem with close friend/relative	31	29	36	26	30	12
None of these	3	2	5	1	3	10
Employment and financial crises						
Made redundant or sacked	61	34	41	51	47	30
Looking for work for 1 month and over	59	27	46	40	43	23
Something valued lost or stolen	36	41	40	38	39	22
Major financial crisis	34	14	20	26	24	11
Problem with police and court appearance	32	12	21	22	22	9
None of these	15	32	25	22	23	46
Vicitimisation experiences						
Bullying	41	41	52	32	41	18
Violence in the home	18	32	32	20	25	7
Running away from home	15	22	30	10	18	5
Violence at work	12	7	9	10	10	4
Being homeless	23	23	29	19	23	4
Sexual abuse	11	31	31	15	21	3
Being expelled from school	5	3	9	1	4	2
None of these	39	37	29	44	38	71
Base	*96*	*101*	*80*	*117*	*197*	*8515*

* Adults aged 16 to 74 living in private households (Meltzer *et al*, 2002, Table 5.7)

Table 7.3 Number of stressful life events by sex and age

	Sex		Age		All
	Male	Female	Under 45	45 and over	
	%	%	%	%	%
Number of stressful life events					
3 or less	20	25	21	23	22
4 or 5	19	22	20	21	20
6 or 7	26	19	19	25	22
8 or 9	19	17	20	16	18
10 and over	18	17	20	15	17
Base	*97*	*103*	*80*	*120*	*200*

Table 7.4 Prevalence of non-fatal suicidal behaviour by number of stressful life events

	Number of stressful life events					
	0–3	4–5	6–7	8–9	10 and over	All
	Cumulative percentage of population					
Suicidal thoughts						
Past week	2	5	2	11	9	6
Past year	16	22	13	40	26	22
Lifetime	56	66	62	86	85	70
Never	44	34	38	14	15	30
Suicide attempts						
Past week	-	-	-	-	-	-
Past year	-	2	7	20	9	7
Lifetime	18	39	43	60	76	45
Never	82	61	57	40	24	55
Deliberate self-harm without suicidal intent	9	12	14	40	38	21
Base	*45*	*41*	*44*	*35*	*34*	*199*

Table 7.5 Prevalence of non-fatal suicidal behaviour by relationship problems

	Relationship problem, illness or bereavement							
	Death of close friend\other relative	Death of close relative	Serious illness or assault	Serious illness or assault to close relative	Separation or divorce	Serious problem with close friend\relative	None of these	All
	Cumulative percentage of population							
Suicidal thoughts								
Past week	7	4	6	5	6	13	-	6
Past year	20	20	27	25	30	26	-	22
Lifetime	66	68	75	76	76	79	[2]	69
Never	34	32	25	24	24	21	[3]	31
Suicide attempts								
Past week	-	-	-	-	-	-	-	-
Past year	6	5	10	12	9	13	-	7
Lifetime	44	44	52	47	57	66	-	44
Never	56	56	48	53	43	34	[5]	56
Deliberate self-harm without suicidal intent	20	21	27	25	25	37	-	21
Base	*108*	*151*	*124*	*59*	*65*	*38*	*[5]*	*196*

Table 7.6 Prevalence of non-fatal suicidal behaviour by employment and financial crises

	Employment and financial crises						
	Made redundant or sacked	Looking for work for 1 month and over	Something valued lost or stolen	Major financial crisis	Problem with police and court appearance	None of these	All
	Cumulative percentage of population						
Suicidal thoughts							
Past week	5	4	7	2	9	9	6
Past year	24	21	25	17	23	20	22
Lifetime	76	74	67	81	74	61	69
Never	24	26	33	19	26	39	31
Suicide attempts							
Past week	-	-	-	-	-	-	-
Past year	10	10	11	6	9	2	7
Lifetime	58	53	44	60	58	35	44
Never	42	47	56	40	42	65	56
Deliberate self-harm without suicidal intent	23	29	23	26	29	15	21
Base	*93*	*83*	*75*	*47*	*43*	*46*	*196*

Table 7.7 Prevalence of non-fatal suicidal behaviour by vicitimisation experience

	Vicitimisation experience								
	Bullying	Violence in the home	Running away from home	Violence at work	Being homeless	Sexual abuse	Being expelled from school	None of these	All
	Cumulative percentage of population								
Suicidal thoughts									
Past week	8	14	17	-	13	17	[1]	1	6
Past year	26	35	33	[6]	40	38	[3]	12	22
Lifetime	76	84	83	[15]	84	86	[8]	59	69
Never	24	16	17	[4]	16	14	-	41	31
Suicide attempts									
Past week	-	-	-	-	-	-	-	-	-
Past year	9	12	14	[1]	11	17	[1]	-	7
Lifetime	57	67	75	[9]	71	74	[8]	24	44
Never	43	33	25	[10]	29	26	-	76	56
Deliberate self-harm without suicidal intent	30	35	42	[7]	36	38	[4]	4	21
Base	*80*	*49*	*36*	*[19]*	*45*	*42*	*[8]*	*74*	*197*

Table 7.8 Odds ratios for characteristics associated with non-fatal suicidal behaviour

	Lifetime suicidal thoughts	Lifetime suicidal attempts	Deliberate self-harm
CIS-R score			
Below 12	1.00	1.00	
12 and over	4.11***	3.61***	
Long standing physical complaint			
Absent	1.00	1.00	
Present	0.41**	0.52	
Number of stressful life time events			
0 – 3		1.00	1.00
4 or 5		2.58	1.47
6 or 7		3.78*	1.90
8 or 9		4.70**	6.53**
10 and over		12.20***	5.67**
Age group			
16 – 34			4.68*
35 – 44			4.76**
45 – 54			2.07
55 – 74			1.00
Other factors entered in the model but not significantly associated with any dependent variable	Sex, employment status, household size, social class, tenure, educational qualifications, sample group		

* = p<0.05; ** = p<0.01; *** = p<0.001

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Appendix A

Assessment of psychosis

A.1 Introduction

The assessment of psychosis requires a more detailed assessment process not normally used in health surveys. We have brought together in this appendix information to help people unfamiliar with the concepts and procedures involved. The aim of this appendix is to help the reader understand the nature of these disorders and some of the difficulties of obtaining samples of adequate size to allow accurate assessment of the prevalence of disorder and the experiences and circumstances of those with disorder.

A.2 Definitions of mental disorder

In this survey report the term mental disorder is used. This terminology can cause concern. The assessment methods used in this survey were based on the World Health Organisation International Classification of Diseases chapter on Mental and Behavioural Disorders (ICD-10) Diagnostic Criteria for Research (DCR). In this report the definition of mental disorder in ICD-10 is used.[1]

The disorder discussed in this report is psychotic disorder, which consists mainly of two types:

- Schizophrenia; and
- affective psychosis, such as bi-polar disorder.

According to ICD-10 the schizophrenic disorders are characterised in general by fundamental and characteristic distortions of thinking and perception. The disturbance involves the most basic mental functions that give the person a feeling of individuality, uniqueness, and self-direction. The most intimate thoughts, feelings, and acts are often felt to be known to, or shared by others. False explanatory beliefs may develop, which are termed delusions. These may include the false belief that natural or supernatural forces are at work to influence the afflicted person, their individual thoughts or actions, which may lead to unusual behaviour by the sufferer. The person may believe they are at the centre of all that happens. Hearing voices or other sounds when there is no one there, termed auditory hallucinations, is common. Perception may also be disturbed in other ways. However memory and consciousness are usually not specifically affected. It will often be apparent from conversation that the sufferer, uncharacteristically, is not thinking logically or fluently. Mood may be shallow or inappropriate to the circumstances. The sufferer may not realise that their feelings and ideas are mistaken, which makes it difficult to collect good and accurate information in a survey about such symptoms. Many sufferers are very disabled by the disorder and the individual's relative inactivity and lack of attention to self-care and personal appearance, although not unique to this disorder, will be regarded by carers and professionals as an important indicator of the course of the condition. The level of disability may make it impossible for the individual to take part in any survey.

The other most common form of psychosis is affective psychosis. This can occur with extreme elation, termed mania, or depression. Disturbances in perception and thinking will typically be related to the mood, either grandiose or extremely hopeless and negative. Heightened mood may be accompanied by rapid speech, over-activity, and reduced sleep. Severely depressed mood may be accompanied by extreme withdrawal from others, total loss of appetite for food and fluids, self-neglect and even stupor. Affective psychosis tends to occur with distinct episodes and recurrences and can respond very well to medical treatment. Once again there is typically severe loss of insight.

A.3 Methods of assessing mental disorders

Diagnostic instruments

For most mental and physical health problems there is no clear dividing line between health and illness. However, it is easier to describe the health of a population and answer important questions about disorders when those with significant health problems can be reliably distinguished using survey interviews. Two approaches for identifying those with significant health problems have been developed. It is conventional to describe these as diagnostic instruments although, in fact, a medical diagnosis is not actually made. The two approaches are termed fully structured and semi-structured.

The first approach comprises of a series of clearly worded questions requiring simple replies such as 'yes', 'no' or 'don't know'. An example would be the question: has your health been good in the past month? The advantage of this fully structured method is that it can be administered by a lay interviewer who does not need any specialised knowledge of health and disease. Therefore the fully structured interview method can be used in very large surveys at an acceptable cost. The disadvantage of the method is that it relies on the knowledge, understanding and insight of the survey respondent. In the case of some complex mental disorders the fully structured method may not be sufficiently accurate.[2]

Making assessments of psychotic disorders is particularly problematic for lay interviewers. A structured questionnaire is too restrictive. A second interviewing approach, sometimes used in surveys, the semi-structured questionnaire, requires the use of clinical judgements. The use of pre-worded fully structured questions with fixed replies, such as yes, or no, or not known will often be inadequate for the purpose and, given the nature of psychotic disorder, would not be suitable for collecting information on symptoms of the kind defined above. An important disadvantage of the semi-structured method is that the interviewer needs special training and clinical experience. Because interviewers use judgement, standardisation is more difficult and more supervision and quality control is therefore desirable. These additional features of semi-structured interviews greatly increase the costs of such surveys and limit the use of the semi-structured method to the more detailed study of selected groups of respondents. The method is often used in two stage surveys, described below.

The Schedules for Clinical Assessment in Neuropsychiatry

One such semi-structured clinical assessment tool designed for use in epidemiological surveys is SCAN (Schedules for Clinical Assessment in Neuropsychiatry[3]). With SCAN the examiner needs to adopt a more flexible approach to respondents than would be appropriate in a fully structured interview. The examiner, who should be a clinically experienced interviewer, makes judgements, using strict guidelines, as to which symptoms are and which are not clearly present. This is not a task for which lay interviewers have the necessary training or experience. The SCAN interview begins with a series of open ended questions in which the respondent is asked to describe their physical and mental health problems using their own words. The SCAN is divided up into separate sections in which specific kinds of symptoms are then enquired about, including mood disturbance and anxiety, hallucinations, delusions, memory problems and problems due to alcohol and drug taking. Every symptom in SCAN is defined in a glossary. The interviewer must decide for each example whether the definition in the glossary matches what the respondent says when asked about that symptom. Thus the method is partially rather than fully structured and is often termed a semi-structured interview. Once the symptoms present have been rated by the clinically experienced interviewer trained in SCAN, the rules for making diagnoses in ICD-10 are used to determine which psychotic disorders are present, i.e. schizophrenia, affective psychoses such as bi-polar disorder. This allocation of a diagnostic category is made by a computer programme in order to ensure total reliability. Thus it is not a medical diagnosis but it does employ rules developed to mimic the clinical diagnostic process.

One versus two stage designs

We pointed out earlier that semi-structured clinical interviews are highly costly but necessary in order to identify correctly survey respondents with significant complex disorders such as psychotic

disorder. To reduce cost, ways have been developed to select those more likely to have such disorders, for whom the more complex assessment is required. In the present example, psychotic disorder, it has been found that survey respondents are more likely to have such a disorder if they are receiving medication for psychosis or if they have previously had a psychiatric admission. In a two stage (or two phase) design the fully structured lay interview is used to ask all survey respondents about their current medication and their history of being in hospital. This is known as sifting or (analogous to screening) for possible cases of psychosis. Those who say yes to such questions are then asked to agree to a second interview, hence the second stage. The second interview, for example with SCAN, is then used to confirm whether or not they really do have psychosis. Because the sift is not perfect some true cases may be missed. Therefore a random sample of those who replied no to the sift questions may also be interviewed in the second stage. However to check for missed cases accurately many 'sift negative' persons need to be assessed with the full semi-structured interview, which also adds to the costs involved. Judgements need to be made about the relative merits of these choices taking account of the costs involved and the benefits in terms of good health survey information.

Making prevalence estimates from 2-stage designs

A two-stage approach was adopted to provide an assessment of psychotic disorder in the household survey. In the first stage interviews, carried out by ONS interviewers, screening questions were included to identify people who might have a psychotic disorder. The factors used to identify people who might have a psychotic disorder had been found in the 1993 survey of psychiatric morbidity among private households and the 1997 survey of psychiatric morbidity among prisoners to be the best predictors of the likelihood of receiving an assessment of psychotic disorder at a second stage semi-structured clinical interview. These were:

- a self-reported diagnosis or symptoms (such as mood swings or hearing voices) indicative of psychotic disorder;
- receipt of anti-psychotic medication;
- a history of admission to a mental hospital; and
- a positive answer to question 5a in the Psychosis Screening Questionnaire which refers to auditory hallucinations.

The presence of any one of these criteria was sufficient for a person to screen positive for psychosis. Then a sub-sample of people were selected to take part in a second stage interview carried out by psychologists employed and supervised by the University of Leicester, who received training and clinical experience with the SCAN interview extending over a month. The people included in the sub-sample can be divided into 3 groups that were selected using different sampling fractions as follows:

- all those who screened positive for psychotic disorder;
- half of those who screened positive for antisocial or borderline personality disorder but not psychosis; and
- 1 in 14 of those who screened positive for other types of personality disorder or screened negative for both disorders.

The second stage interviews used the SCAN v2.1 (Schedules for Clinical Interviews in Neuropsychiatry[4]), a semi-structured interview which provides ICD-10 diagnoses of psychotic disorder.

An assessment of the prevalence of psychotic disorder could be obtained by simply weighting the results from the sub-sample who had a second stage SCAN interviews to take account of varying sampling fractions and non-response. However, there are problems with this approach:

1. The second stage sample design included a SCAN assessment of people who screened negative for psychosis in the first stage interview which allows some assessment of the prevalence of psychotic disorder among this group who are likely to be cases that are unknown to services. However, the bulk of the positive cases are likely to be in the screen positive group and logistic regression analysis showed that the most important predictor of a positive SCAN assessment among the stage 2 sample was the presence of one or more of the screening criteria, and that the odds of a positive assessment increased dramatically the more criteria were

present. However, there were some positive cases among those who screened negative and because of the different sampling fractions used, these cases get a much higher weight than the majority of cases which occurred among the screen positives. The effect of the wide range of weights is to produce an estimate with a high coefficient of variation (the sampling error as a proportion of the estimate itself) with a very wide confidence interval around it, which is shown (estimate 1) in Table A1. Thus for all adults the prevalence estimate is 1.1% with a 95% confidence interval ranging from 0.5% to 1.7% while for women the prevalence estimate is 1.6% with a 95% confidence interval ranging from 0.4% to 2.7%. Estimates which cover such a wide possible range are very difficult to use for policy purposes, eg for predicting the numbers of people who might require services, or for monitoring trends over time.

2. The comparatively small size of the sub-sample which completed a second stage interview limits the amount of additional analysis, such as co-occurrence of disorders and social and economic factors associated with disorders, which can be done using this second-stage sample only. Therefore there is a requirement for some measure of probable/possible disorder for the sample as a whole to be used for these types of analysis and for the consideration of variations in prevalence of disorder among different sub-groups.

The results obtained from the second stage interviews can be viewed as belonging to two groups for whom the prevalence of psychotic disorder can be obtained with different degrees of precision. The first group is people who screen positive for psychotic disorder from which we have SCAN assessments for all who agreed to a second interview. The prevalence of disorder is comparatively high amongst this group and a high proportion were interviewed, so the confidence interval is relatively narrow as is shown in Table A1. The prevalence estimate for this group is 13.3% (95% CI 8.1%–18.6%) and the coefficient of variation (CV) is 20%.

The second group are those who screened negative for psychotic disorder. Among this group psychotic disorder is likely to be extremely rare and, since only a small proportion could be included in the second stage of the survey, any estimate of the prevalence among this group will be extremely imprecise. The sample of screen negatives taken was small and alternative random samples of screen negatives would quite possibly have given very different estimates. The prevalence estimate obtained for this group is 0.6% (95% CI 0.0%–1.2%), which is very much lower than in the screen positive group but is much less precise having a CV of 47%, double that of the screen positive estimate. In this sample all the false negatives on the psychosis screen were found among women – a fact which is reflected in the wide confidence intervals around the estimate for women shown in estimate 1 in Table A1. This might be due to true differences in prevalence between men and women, differences in responses to the screening questions, differences in the way the SCAN interviewers interpreted symptoms between men and women or a chance finding resulting from the sampling for the second stage. There was no difference between men and women in the proportion screening positive for psychosis. However, women were more likely than men to receive a positive SCAN assessment when other factors, such as the presence of different screening criteria, were controlled for and it appeared that the psychosis screen worked better for men than for women. Comparison between the detailed responses in the SCAN interviews for the false negative cases and other positive cases showed no apparent differences, except that the screen negatives were not receiving services and did not show evidence of significant disability or distress. It may be that men with psychotic disorder are more likely than women to be known to services and receiving treatment, but the difference between the men and women shown in estimate 1 is not statistically significant indicating that it could just be an artefact of the particular sample selected in the survey.

The finding of some screen negatives does suggest that a prevalence rate based solely on screen positives (estimate 2) is likely to be an underestimate. However, in view of the wide confidence interval, it is also quite possible that estimate 1, which includes the screen negatives,

may be itself a substantial overestimate. Therefore, it was decided that it would not be useful to use the prevalence estimate which includes the SCAN data from screen negatives in the report because of the imprecision and uncertainty associated with it. It is recognised that any estimate that does not take account of false negatives on the screen will be an underestimate, but the extent of that underestimate and the importance of it is uncertain. However, the estimate adopted is more stable and therefore more use for policy analysis and monitoring trends. The problem of obtaining an assessment of psychotic disorder for those people who sifted positive for psychosis but did not have a SCAN interview because they refused a second interview or could not be contacted at that time was dealt with slightly differently in the earlier 1993 survey of adults in private households and the 1997 survey of prisoners. In both cases the relationship between the initial interview data and the SCAN assessment data for those who completed both stages was considered to identify factors indicative of likely psychotic disorder. In 1993, those taking antipsychotic medication and who reported that they had a psychotic illness or that their doctor told them they had such an illness were considered as having a functional psychosis. In the survey of prisoners there was some additional information available and it was found that the presence of any two of the sift criteria described above was a better indicator of probable psychosis. In this survey data, there continued to be a good relationship between the screening criteria and the likelihood of a positive SCAN assessment and it was decided to use the same approach as adopted in the 1997 prison survey for providing an assessment of probable psychosis for those people who sifted positive for psychosis but did not complete a SCAN interview. In summary, the assessment of probable psychosis used in this survey was obtained for individual respondents as follows:

- For those who sifted positive for psychosis and undertook a SCAN interview, the SCAN assessment was used.
- For those who sifted positive for psychosis but did not complete a SCAN interview, an assessment based on whether or not they reported two or more of the screening criteria at the initial interview was applied.
- All those who screened negative for psychosis at the initial interview were designated psychosis negative regardless of whether or not they had undertaken a SCAN interview.

The prevalence estimates obtained in this way are shown in Table A1 and in relation to some basic classificatory variables in the main survey report.[5]

Obtaining samples of people with psychotic disorders for separate analysis

Because psychosis is quite rare in the general population even in a large survey very few cases will be identified. Large samples are needed to study these individuals and describe their characteristics reliably. Another source for such persons needs to be considered. It is important that the source chosen is typical and thus represents the general population. Because these disorders are severe and disruptive the majority of sufferers are thought to come to the attention of medical services such as the general practitioner. Therefore a sample could be obtained from general practices. However there needs to be some way of identifying such persons within the practice records in order to draw a random and thus representative sample. We used records held by the General Practice Research Database (GPRD). There are problems with such approaches. One is relying on the accuracy of a register database that must to be kept up to date by often very busy general practitioners. Secondly, because of the vulnerability of such patients, doctors and research ethics committees may feel that it is necessary to screen potential cases and identify those who might be harmed by the survey interview. This in turn means having to rely on the help, effort and co-operation of the general practitioner and also means that the final sample obtained may not be representative. In addition, the requirement for maintaining confidentiality of medical records means that such patients must be approached by their GPs or other medical staff and asked to opt-in to the survey or give permission for their details to be released to the organisation conducting the research. This also reduces the response rate as reminders cannot be issued and the opportunity to provide additional information to help people make a decision on whether or not

to participate is usually lost. For all of these reasons it is not possible to obtain the level of co-operation and the response rate that surveyors have been accustomed to when approaching the general public in a general household survey.

A.4 The approach used in this report

The main purpose of this report is to describe the characteristics and living circumstances of people with psychotic disorder and to provide information on the services and treatment they receive. The main household survey only identified 60 people with a psychotic disorder, which limits the power of any analysis. Therefore the analysis in this report brings together people with psychotic disorders identified in the main household survey, and those located through a supplementary sample. This sample was obtained from records held by the General Practice Research Database (GPRD). Selection was on the basis of a diagnosis indicating schizophrenia, affective psychoses such as bi-polar disorder, or a prescription for anti-psychotic drugs. The details of the selection procedures and the response obtained is given in Chapter 1.

References

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2 Brugha T S, Bebbington P E and Jenkins R (1999). A difference that matters: comparisons of structured and semi-structured diagnostic interviews of adults in the general population. *Psychological Medicine* **29,** 1013–1020.

3 Wing J K, Babor T, Brugha T, Burke J, Cooper J E, Giel R, Jablensky A, Regier D and Sartorius N (1990) SCAN: Schedules for Clinical Assessment in Neuropsychiatry. *Archives of General Psychiatry* **47**, 589–593.

4 World Health Organisation Division of Mental Health (1999) *SCAN Schedules for Clinical Assessment in Neuropsychiatry Version 2.*1, World Health Organisation: Geneva.

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Table A1 Alternative estimates of psychosis prevalence

Assessment based on ...	Sample size	Prevalence Estimate (percentage)	95% CI* LL	95% CI* UL	Sampling Error	CV**
1. SCAN interviews only – including screen negatives						
Men	272	0.65	0.32	0.98	0.17	26%
Women	351	1.57	0.41	2.73	0.59	37%
All adults	623	1.11	0.52	1.70	0.30	27%
People who screened positive	203	13.31	8.06	18.56	2.68	20%
People who screened negative	420	0.63	0.04	1.22	0.30	47%
2. SCAN or prisons algorithm for screen positives (screen negatives assumed negative)						
Men	3,852	0.57	0.35	0.79	0.11	19%
Women	4,728	0.49	0.31	0.67	0.09	20%
All adults	8,580	0.53	0.37	0.69	0.08	15%

*95% confidence interval; LL=lower limit, UL=upper limit.
**Coefficient of Variation = Sampling Error/Estimate.

Appendix B

Multiple logistic regression and odds ratios

Logistic regression analysis has been used in the analysis of the survey data to provide a measure of the effect of, for example, various characteristics on the receipt of medication among this sample of people with psychotic disorder. Unlike the cross tabulations presented elsewhere in the report, multiple logistic regression (MLR) estimates the effect of any variable while controlling for the confounding effect of other variables in the analysis.

Logistic regression produces an estimate of the probability of an event occurring when an individual is in a particular category compared to a reference category. This effect is measured in terms of odds. For example, Table 2.10 shows that having a CIS-R score of 12 and over increases the odds of having consulted a GP in the past year compared to the reference category of CIS-R score below 12. The amount by which the odds are actually increased is shown by the Adjusted Odds Ratio (OR). In this case the OR is 2.72 indicating that if someone has a CIS-R score of 12 and over the odds that they will consult their GP are almost trebled, controlling for the possible confounding effects of the other variables in the statistical model. To determine whether this increase is due to chance rather than to the effect of the variable one must consult the associated 95% confidence interval and p values. In tables showing adjusted odds ratios, ORs which are statistically significant at the 95% level are indicated by a single asterisk * and ORs which are statistically significant at the 99% level are indicated by double asterisks **.

Odds ratios and how to use them multiplicatively

The odds ratios presented in the tables show the adjusted odds due solely to membership of one particular category – for example having a CIS-R score on or above the threshold of 12 compared with those with a score below the threshold. However, odds for more than one category can be combined, by multiplying them together. This provides an estimate of the increased odds of having high levels of neurotic symptoms due to being a member of more than one category at once. For example, being someone aged 45 and over and having a high CIS-R score. In Table 2.10 having a high CIS-R score increases the odds of consulting a GP in the year before interview (OR=2.72), while being aged 45 and over (compared to those aged under 45) independently decreases the odds (OR=0.44). The odds for people aged 45 or over and having high CIS-R scores compared with younger people with low scores is therefore the product of the two independent odds ratios, 1.20.

Glossary of survey definitions and terms

Adults

In this survey adults were defined as persons aged 16 and over and less than 75.

Alcohol dependence

Alcohol misuse was measured using two different instruments. First the Alcohol Use Disorders Identification Test (AUDIT) was used to assess hazardous drinking (see below). Those who scored 10 and over on the AUDIT were also asked the Severity of Alcohol Dependence Questionnaire (SAD-Q). People who scored 4 and over on the SAD-Q were considered to be dependent on alcohol.

Analgesic, hypnotic and anxiolytic medication

Analgesics are drugs for relieving pain, while hypnotics and anxiolytics are drugs used for treating sleep problems and for reducing anxiety.

CIS-R (Clinical Interview Schedule – revised version)

The CIS-R is an instrument designed to measure neurotic symptoms and disorders, such as anxiety and depression. It comprises 14 sections each covering a particular type of neurotic symptoms. Scores are obtained for each symptom based on frequency, duration and severity in the past week. Individual symptom scores can be summed to provide an overall score for the level of neurotic symptoms. A score of 12 and over indicates the presence of significant levels of neurotic symptoms while a score of 18 and over indicates symptoms of a level likely to require treatment. If required, diagnoses of 6 specific neurotic disorders can be obtained by looking at answers to the various sections of the CIS-R and applying algorithms based on the ICD-10 diagnostic criteria for research.

Depot injections

When antipsychotic medication is given by injections on, for example, a monthly basis, these are sometimes termed depot injections.

Drug dependence

In the year prior to interview drug dependence was measured by asking all those who had used drugs in the past year a series of five questions. These covered: daily use of the drug for two weeks or more; feelings of dependence; inability to cut down; need for increasing quantities; withdrawal symptoms. For a person to be considered dependent, a positive response to any one of these questions was required.

Drugs used in psychoses etc

Drugs used in psychoses and related conditions include antipsychotic drugs, including depot injections. These are also known as 'neuroleptics'. In the short term they are used to quieten disturbed patients whatever the underlying psychopathology (see depot injections). Also included in this group are antimanic drugs which are used in mania to control acute attacks and prevent their recurrence.

Economic activity

Economically active persons are those over the minimum school-leaving age who were working or unemployed in the week before the week of interview. These persons constitute the labour force.

Working persons

This category includes persons aged 16 and over who, in the week before the week of interview, worked for wages, salary or other form of cash payment such as commission or tips, for any number of hours. It covers persons absent from work in the reference week because of holiday, sickness, strike or temporary lay-off, provided they had a job to return to with the same employer. It also includes persons attending an educational establishment during the specified week if they were paid by their employer while attending it, people who worked in Government training schemes and unpaid family workers.

Persons are excluded if they have worked in a voluntary capacity for expenses only, or only for payment in kind, unless they worked for a business, firm or professional practice owned by a relative.

Full-time students are classified as 'working', 'unemployed' or 'inactive' according to their own reports of what they were doing during the reference week.

Unemployed persons

This survey used the International Labour Organisation (ILO) definition of unemployment. This classifies anyone as unemployed if he or she was out of work in the four weeks before interview, or would have been but for temporary sickness or injury, and was available to start work in the two weeks after the interview. Otherwise, anyone out of work is classified as economically inactive.

The treatment of all categories on this survey is in line with that used in the Labour Force Survey (LFS).

For most of the analyses in the report a variable which divided the sample into economically active (working or unemployed) or economically inactive (everyone else) was used.

Educational level

Educational level was based on the highest educational qualification obtained and was initially grouped as follows:

1. Degree or higher degree
   NVQ Level 5

2. Teaching qualification
   HNC/HND
   BRC/TEC Higher
   BTEC/SCOTVEC Higher
   City and Guilds
   Full Technological Certificate
   Nursing Qualifications (SRN, SCM, RGN, RM, RHV, Midwife)
   NVQ Level 4

3. GCE A levels and AS levels
   SCE Higher
   ONC/OND/BTEC/TEC/BTEC not higher
   City and Guilds Advanced/Final Level
   GNVQ (Advanced Level)
   NVQ Level 3

4. GCE O level passes (Grade A–C if after 1975)
   GCSE (Grades A–C)
   CSE Grade 1
   SCE Ordinary (Bands A–C)
   Standard Grade (Level 1–3)
   School Certificate or Matric
   City and Guilds Craft/Ordinary Level
   GNVQ (Intermediate level)
   NVQ Level 2

5. CSE Grades 2–5
   GCE O level Grades D and E after 1975
   GCSE (Grades D,E,F,G)
   SCE Ordinary (Bands D and E)
   Standard Grade (Level 4,5)
   Clerical or Commercial qualifications
   Apprenticeships
   NVQ Level 1 and GNVQ (Foundation Level)
   CSE ungraded

6. No formal qualifications

For most of the analyses in this report these groupings were collapsed into three categories: 'A' levels or above which covers the first three groups, Other qualifications which includes all other groups except the last one, and None which equates to the 'No formal qualifications' group above.

Ethnicity

Household members were classified into nine groups by the person selected for interview. For analysis purpose these nine groups were subsumed under 4 headings: White, Black, South Asian and Other.

White	White
Black – Caribbean	Black
Black – African	
Black – Other	
Indian	South Asian
Pakistani	
Bangladeshi	
Chinese	Other
Other	

Hazardous alcohol use

Hazardous alcohol use is a pattern of drinking carrying with it a high risk of damage to health in the future. The prevalence of alcohol misuse in the previous year was assessed using the Alcohol Use Disorders Identification Test (AUDIT) at the initial interview. An AUDIT score of eight or above indicates hazardous alcohol use.

Household

The standard definition used in most surveys carried out by ONS Social Survey Division, and comparable with the 1991 Census definition of a household, was used in this survey. A household is defined as single person or group of people who have the accommodation as their only or main residence and who either share one meal a day or share the living accommodation. (See E McCrossan *A Handbook for interviewers*. HMSO: London 1991)

Household size

Basic information (age, sex, ethnicity and relationship to others in the household) was collected from the informant about all people living in the household. This was used to produce a variable for the number of people living in the household.

Intellectual functioning

Three tests were included in the survey to measure different aspects of intellectual functioning. All participants completed the National Adult Reading Test (NART), a measure of crystallised intelligence, reflecting the extent of intellectual development by adulthood. Scores on the NART have then been translated into estimated verbal IQ scores on the WAIS-R using the algorithm recommended by the developers of the NART.

Those aged 60 and over also completed two tests likely to be sensitive to cognitive decline associated with ageing or dementia. The modified Telephone Interview for Cognitive Screening (TICS-m) was developed as a brief screening test for dementia. Those scoring below a cut-point have a high probability of significant cognitive impairment, and of meeting criteria for a clinical diagnosis of dementia. The animal naming test assesses verbal fluency, in this case the number of different animals a participant can name in one minute.

Long-standing physical illness

All respondents were asked if they had any long-standing illness, disability or infirmity, that is any thing that had troubled them over a period of time or was likely to affect them over a period of time. If they had any such conditions they were then asked what they were. Anyone who mentioned a physical health problem at this question was classified as having a long-standing physical illness or health problem.

Marital Status

Informants were categorised according to their own perception of marital status. Married and cohabiting took priority over other categories. Cohabiting included anyone living together with their partner as a couple.

Neurotic disorders, depression or anxiety disorders

These are characterised by a variety of symptoms such as fatigue and sleep problems, forgetfulness and concentration difficulties, irritability, worry, panic, hopelessness, and obsessions and compulsions, which are present to such a degree that they cause problems with daily activities and distress. The prevalence of neurotic symptoms in the week prior to interview was assessed using the revised version of the Clinical Interview Schedule (CIS-R) (see above). A score of 12 and over indicates the presence of significant neurotic symptoms while a score of 18 and over indicates symptoms of a level likely to require treatment.

Psychiatric Morbidity

The expression psychiatric morbidity refers to the degree or extent of the prevalence of mental health problems within a defined area.

Psychoses

These are disorders that produce disturbances in thinking and perception that are severe enough to distort the person's perception of the world and the relationship of events within it. Psychoses are normally divided into two groups: organic psychoses, such as dementia and Alzheimer's disease, and functional psychoses, which mainly cover schizophrenia and manic depression.

Region

When the survey was carried out there were 8 NHS Regional Office Areas in England. These were the basis for stratified sampling and have been retained for purposes of analysis. Scotland and Wales were treated as two distinct areas.

Social Class

Based on the Registrars general's 1991 *Standard Occupational Classification,* Volume 3 OPCS, HMSO: London social class was ascribed on the basis of the informants own occupation. If the informant was unemployed or economically inactive at the time of interview but had previously worked, social class was based on the most recent previous occupation.

The classification used in the tables are as follows:

Descriptive Definition	Social Class	
Professional	I	Non-manual
Intermediate occupations	II	
Skilled occupations – non-manual	III NM	
Skilled occupation – manual	III M	Manual
Partly-skilled	IV	
Unskilled occupations	V	
Armed Forces		

Social class was not determined where the subject had never worked, or if the subject was a full-time student or where occupation was inadequately described.

Tenure

Four tenure categories were created:

'Owned outright' means bought without a mortgage or loan or with a mortgage or loan which has been paid off.

'Owned with mortgage' includes co-ownership and shared ownership schemes.

'Rent from LA/HA' means rented from local authorities, New Town corporations or commissions or Scottish Homes, and housing associations which include co-operatives and property owned by charitable trusts.

'Rent from other source' includes rent from organisations (property company, employer or other organisation) and from individuals (relative, friend, employer or other individual).

For the analyses in this report these were then grouped into two groups: owners (including those who owned their home outright and those purchasing their homes with a mortgage) and renters (those renting from any source).