Systematic Review of the Incidence and Prevalence of Schizophrenia and Other Psychoses in England

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EXECUTIVE SUMMARY

Background (Chapter 1)
The Department of Health commissioned this series of systematic reviews on the incidence and prevalence of schizophrenia and other psychotic disorders in England. Incidence\(^1\) is the number of people who develop an illness for the first time, per year, in a given place; prevalence is the proportion of a defined community who already have or develop an illness at a particular time or during a specified period. Psychotic disorders are a group of mental illnesses characterised by delusions, hallucinations and other problems of thought and emotion. Schizophrenia is a particular type of psychotic disorder, as are affective psychoses that can include psychotic depression and bipolar disorder. In this summary we concentrate on all psychoses as a broad group, and on schizophrenia and affective psychoses as two main sub-types of psychotic disorders; the full report contains a more detailed breakdown.

The incidence of psychotic disorders was once thought quite similar across populations and communities but it now seems that there are big differences. It is important to understand these differences in order to meet the needs of service users and carers in early intervention services (EIS) and other mental health services. Understanding differences is also vital for prevention. Psychotic disorders can cause great disability for sufferers and burden for families. They are expensive to society due to the costs of care and treatment and to lost work opportunities for some sufferers, particularly as their onset is often in young adult life.

Aims (Chapter 2)
1. Systematically review the existing evidence from the past 60 years regarding the incidence and prevalence of all psychotic disorders, schizophrenia and affective psychotic disorders in England
2. Identify variation in the incidence and prevalence by sociodemographic (e.g. age, sex, social class, ethnicity) and geographical factors

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\(^1\) See full report Glossary for explanation and definition of all terms in bold indigo text
3. Understand whether rates have changed over time, particularly regarding the introduction of EIS in England from 2002 and concerns that increasing use of cannabis may lead to psychotic illness

4. Estimate the costs related to variation in incidence and prevalence of psychotic disorders

Methodology (Chapter 3)
The study team comprised librarians, information scientists, statisticians, psychiatrists, psychologists, health economists, social scientists and epidemiologists. Using key search terms we identified all published and unpublished studies of the incidence or prevalence of psychotic disorders, conducted wholly or partially in England, between 1950 and 2009. Electronic databases (MEDLINE, PsychINFO, EMBASE, CINAHL, ASSIA, HMIC) were searched, as were the published papers that this search identified. We wrote to researchers to identify missed or unpublished studies. Scientists sometimes publish many reports from one study so we made sure we included any study only once. We assessed each one for quality and extracted the information on incidence and prevalence. We identified all the studies, assessed their precision and quality, judged whether studies give a similar message and then, where possible, pooled all equivalent information from the best and most comparable studies. This simple method answered many questions such as whether these disorders are more common in men, whether different age groups are affected and whether some ethnic groups have a greater burden of psychotic disorders. Sometimes more complex techniques were used to make the information from different studies more comparable (regression) or to use studies from different situations in order to answer an over-arching question (meta-regression). For example, we used meta-regression to find out whether schizophrenia occurred more commonly in densely populated city communities than in towns or rural areas because virtually no single study covered all types of environment; they just studied either a city or a rural area, not both. We took a similar approach to looking at changes over time because no study of rates covered the whole 60 year time period. Our review provided more information on these and other questions than had ever before been assembled for England. An international scientific group advised the process. Independent experts reviewed our work that we updated in the light of their detailed comments.
**Results (Chapter 4)**

We identified 5,262 potentially important and relevant publications; 227 were from the “grey” or non-scientific literature. A further 30 (one unpublished) were identified by searching the papers and asking researchers. Our work is based on 148 individual studies that met our inclusion criteria (see main report Figure 4.1).

**All psychotic disorders (Section 4.2.1)** had an overall (pooled) annual incidence of 32 cases per 100,000 people. Incidence was higher in men than in women before age 45, but more equal, thereafter. Rates for black and minority ethnic (BME) groups were much higher than in the comparison population. This was a very consistent finding from all studies, obvious without the more complex techniques, and generally consistent for men and women (main report, Section 4.2.1.3). Several types of study found no compelling evidence of changes in incidence over time (main report, Section 4.2.1.4) or of significant urban-rural differences. None of these effects was affected by study quality.

**Schizophrenia (Section 4.2.3)** showed a pooled annual incidence of 15 per 100,000 people. There was a much higher incidence in younger men compared with women, and for BME groups compared with the majority; most of the studies supported this finding. Incidence was relatively stable over time. Any increases that were found could be explained by changes in the ethnic make-up of the relevant community. There was evidence for variation according to social disadvantage with higher rates in more disadvantaged communities and neighbourhoods. None of these effects was dependent on study quality.

**Affective psychoses (Section 4.2.4)** had a pooled annual incidence of 12 per 100,000 people. Unlike schizophrenia, men and women had a similar incidence that decreased with age. Affective psychoses were more common in BME groups but appeared not to have become more or less common since 1950. In contrast to schizophrenia, there was no evidence of any geographical or neighbourhood effects on incidence.

**Rates in early intervention services (EIS) for psychosis compared with rates from other studies** (main report, Section 8.2.1). The search identified one conference abstract and one paper studying rates in EIS. Comparing these rates with a large study undertaken before EIS were
implemented indicated that there are more (rates 75% higher) young people being treated by these EIS than were expected when they were commissioned.

**Prevalence (Chapter 5)**

Studies of the prevalence of all psychotic disorders showed considerable variation in methodology, quality and in results so were more difficult to pool. Overall, the studies suggested that 4 people from every 1000 have, or have had an active psychotic disorder over the past year (annual prevalence). This increases with age but has not risen over the 60 years we reviewed. Most of the burden from current, rather than new psychosis (that is prevalence rather than incidence) comes from schizophrenia. However, some affective psychoses like bipolar disorder keep coming back so are a greater burden on people and more expensive than might be expected; this is considered, below.

The literature from **specialised, institutional settings (Chapter 6)** contained a mixture of methods and approaches. Prevalence of psychotic disorder was consistently much higher in these settings (i.e. judicial & custodial services, homeless shelters, residential homes) than in the general population.

**Costs for services and society (Chapter 7) were** estimated as the annual economic burden of these disorders in relation to the total UK population in 2009. We based these estimates on the prevalence data identified in Chapter 5 and recent estimates of relevant costs in the UK.

The total cost per year of a broadly defined schizophrenia (non-affective psychoses) was placed at £8.8bn. Service costs contributed £3.5bn (40%) to this, and informal care £1.2bn (13%). Lost employment was the single largest cost to society (£4.1bn per annum; 47%). Costs were slightly higher for men (£4.8bn; 55%) than women (£4.0bn; 45%), reflecting the prevalence of disorder. Psychiatric inpatient care represented the single largest service cost (£1.7bn). The distribution of costs for schizophrenia as a separate outcome was similar, with an annual estimated cost to the UK of £5.25bn.

For **affective psychosis** the total cost to UK services and society per annum was almost to the same as the cost of schizophrenia (£5.0bn), reflecting the higher per-patient costs associated
with bipolar disorder in spite of its lower prevalence. In contrast to non-affective psychoses, the majority of this figure came from NHS costs (£4.05bn; 80%). Informal care costs (£167m; 3%) and costs of lost employment (829m; 16%) were relatively low.

Discussion & Conclusions (Chapter 8)
We considered more evidence about the incidence and prevalence of psychotic disorders in England than has ever before been brought together. The results are important for the NHS. These conditions more commonly arise in young adults than older people, in men, in the BME groups studied, in cities and in poorer neighbourhoods. Therefore, the needs of some communities will differ greatly from the needs of others, with variation apparent at a local level. This variation must be taken into account during service commissioning; one size does not fit all communities. Our work could be developed into a practical prediction tool for commissioners and those providing mental health services. Psychotic disorders are enormously expensive so it is important to get the services right.

The proportion of BME groups in an area has an important bearing upon incidence of psychosis in that locality. The raised rates in BME groups were consistent across studies, were not confined to schizophrenia, were demonstrated in the highest quality studies designed to investigate the issue, and did not require sophisticated statistical methods to show the effect. The review does not show why some BME groups are at greater risk of psychosis. Factors such as age, sex, urbanicity and socio-economic disadvantage are important in all communities, including BME groups. Psychological stressors make important contributions to the cause of psychosis and may be more common in the BME groups that have been studied. There needs to be more research into this important issue and strenuous efforts to provide the right services. We do not know what is happening in the recently migrated populations such as those from the former Soviet Union or Eastern Europe; further epidemiological research is required.

There was no evidence that the incidence of psychotic illnesses has increased over time in the way that might have been expected if increased cannabis use were having an effect. However, there have been recent increases in the strength of commonly used cannabis preparations so there needs to be continued vigilance in the years ahead.
There are few studies of prevalence, a very basic parameter. Improved NHS clinical information systems could help improve our knowledge of this area. Studies revealed fewer differences in prevalence between population groups and geographical areas than we found for incidence. Illnesses such as schizophrenia represent the main, on-going personal and economic burden but the costs of other illness such as bipolar disorder were also very high.

**Recommendations (Chapter 8)**

1. Service commissioners and planners should take into account the detailed variation in incidence of psychotic disorders, particularly non-affective psychoses (schizophrenia) at the local population level.

2. The greatest driver of variation in incidence, once the age, sex and socio-economic structure of a population is taken into account, is the proportion of people from BME communities. This has to be acknowledged at the service planning and political level, with more research being required to understand this important phenomenon. Future changes regarding recent migrant groups need to be studied.

3. DH should commission the development of a prediction tool that integrates small-area (local) population data and the findings from the review. This would produce information about the numbers of people each year who will develop a psychotic illness (population need) in any given area. This would ensure that services can be designed to meet population need and would greatly help commissioners and service providers.

4. In addition to the prediction tool (Recommendation 3), the numbers of people being treated for first onset psychosis (administrative incidence) should be studied through EIS so as to refine prediction and to ensure that services are being planned and delivered properly. Some EIS may have much higher caseloads than were expected; others may have lower caseloads. A prediction tool and the routine monitoring of administrative incidence would reduce the likelihood of a mismatch between population need, commissioning and the services provided.

5. New NHS information systems should be routinely used to collect current and future information on the variation in (administrative) incidence and prevalence of these disorders. This will support service delivery and research into the causes of illness.
6. Social factors in the urban environment, including indicators of low community cohesion, were associated with increased incidence rates of schizophrenia. Further research into these factors may reveal prevention opportunities and help unravel the multilevel causes of psychosis. This is a public health priority.
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Further details of this report, supplemental tables and files can be downloaded from www.psychiatry.cam.ac.uk/epicentre