Report of a working group
to the Department of Health

SEVERE MENTAL
ILLNESS

outcome

indicators

health
FOREWORD

The Government consultation document “A First Class Service - Quality in the new NHS”, published in 1998, emphasised three essential aspects of ensuring delivery of high quality of care by the National Health Service: setting, delivering and monitoring standards. It also discussed the importance of partnership between the Government and the clinical professions and patients in achieving such quality.

This series of 10 reports concerns the third aspect - monitoring standards. It represents the culmination of work that was started several years ago under the auspices of the Clinical Outcomes Group, chaired jointly by the then Chief Medical Officer, Sir Kenneth Calman, and the Chief Nursing Officer, Dame Yvonne Moores. The work was commissioned by the former Central Health Outcomes Unit of the Department of Health. The Unit has since moved and is now called the National Centre for Health Outcomes Development (NCHOD), based jointly at the Institute of Health Sciences, University of Oxford and the London School of Hygiene and Tropical Medicine, University of London.

The background to the work was the need to ensure that the NHS is driven by considerations of quality and outcome. The Department wanted to build on an earlier set of Population Health Outcome indicators, which had been limited by the constraints of existing routine data. It therefore commissioned systematic work on ten clinical topics, to be undertaken by a Working Group on each, tasked to make recommendations on ‘ideal indicators’ for each condition. ‘Ideal indicators’ were defined as statistical measures of what should be known, and realistically could be known, about the outcomes of the condition in routine clinical practice. The Groups were asked to consider a wide spectrum of possible uses of outcome indicators, from national monitoring of NHS performance by government to the periodic assessment of local services by clinicians and users.

The work of the Working Groups was coordinated by Michael Goldacre, University of Oxford. A particular feature of the work is that the Groups have recommended definitions and technical specifications for each indicator. It is hoped that people interested in monitoring the topic covered by each indicator will use the same definitions so that comparisons can be facilitated. Moreover, the methodology adopted by the Working Groups is applicable to developing health outcome indicators for many other conditions.

The publication of these reports, however, is only one further step on a long road of quality assessment in health care. The reports present ‘menus’ of suggestions for ways in which outcomes might be monitored in a variety of settings, by a variety of organisations and people. It goes without saying that NCHOD will welcome feedback on the reports and on the development and use of outcome indicators.

I believe that the work described here shows the value and potential of partnerships between various parties. Each working group had members who brought together perspectives of all the relevant clinical professions plus patients, NHS managers, policy makers, researchers and others as appropriate. The recommendations of the Working groups show quite clearly how these various perspectives may contribute to a broader and more balanced monitoring of standards. I would personally like to congratulate and thank everyone who has worked so hard and well to bring this initiative to fruition.

Azim Lakhani (Director - National Centre for Health Outcomes Development)

CONTRIBUTORS TO THIS REPORT

Chair: Pamela Charlwood


Support groups: Unit of Health-Care Epidemiology, University of Oxford: Michael Goldacre (Project Co-ordinator), Alastair Mason, John Fletcher, Ewan Wilkinson.
CASPE Research, London: Robert Cleary, James Coles
NHS Centre for Reviews and Dissemination, University of York: Alison Eastwood
UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds: Joanne Greenhalgh.

Edited by: Pamela Charlwood, Alastair Mason, Michael Goldacre, Robert Cleary and Ewan Wilkinson for the Working Group on Outcome Indicators for Severe Mental Illness.

# OUTCOME INDICATORS FOR SEVERE MENTAL ILLNESS

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SUMMARY OF RECOMMENDATIONS

Using a variety of check lists including a health outcome model, the Group identified outcome indicators which were fully specified in a standard format and are included in this Report. Outcome indicators, whose numbers correspond to the specifications in Section 4, were grouped under nine headings relating to the aim of the intervention.

Recommendations for implementation were made for each indicator using the following categories:

A. To be implemented generally by periodic survey.
B. To be implemented where local circumstances allow by periodic survey.
C. To be implemented following IT development on a routine basis.
D. To be further developed either because link with effectiveness is not clear or the indicator specification is incomplete.

For some indicators recommendations have been given initially and in the longer term. The categories shown below are the initial recommendations but the indicators marked * should in the long term become category C and those marked ** category A.

Indicator related to reduction or avoidance of risk of SMI

1. Prevalence of SMI.

Indicator related to detection of SMI early

2. In-patient admission on detection of SMI.

Indicators related to maintenance of function and reduction of need for hospital admission

3. HoNOS scores for a service provider population of people with SMI.
4. Proportion of people with SMI lost to follow-up by specialist services.
5. Proportion of people with SMI discharged from follow-up by specialist services.
6. Proportion of people with SMI spending more than 90 days in a given year in in-patient psychiatric care.

Indicators related to restoration of function and reduction of relapse following hospital admission

7. Longitudinal indicators of change in item, subscale and total HoNOS scores among people with SMI admitted to in-patient psychiatric care.
8. Hospital re-admission frequencies for a resident population of people with SMI.
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1. INTRODUCTION TO THE REPORT

Health outcome indicators

1.1 This Report is one of a series containing the recommendations of working groups set up to develop ‘ideal’ indicators of the health outcomes of specific conditions. The background to the work, commissioned by the Department of Health, is summarised in Appendix A.

1.2 Health outcomes have been defined as changes in health, health related status or risk factors affecting health, or lack of change when change is expected. They may be the result of the natural history of the condition or may be the effect of interventions to prevent or treat it. The particular concern of the working groups has been to make recommendations about outcomes which may be attributable to interventions or the lack of them.

1.3 The term ‘indicator’ has been defined as an aggregated statistical measure, describing a group of patients or a whole population, compiled from measures or assessments made on people in the group or the population. An indicator may not necessarily provide answers to whether care has been ‘good’ or ‘bad’; but well chosen indicators, as the term implies, should at least provide pointers to circumstances which may be worth further investigation.

1.4 An ‘ideal’ indicator has been taken to mean what should be known, and realistically could be known, about the outcomes of the prevention and care of specific conditions. The development of the recommendations has, of course, been tempered by considerations of the likely cost and availability of information. However, the working groups have tried to be reasonably far-sighted in their views about future advances in information systems.

1.5 For each condition the working group has developed a menu of indicators which can be used by different groups of people for a variety of purposes. In particular, an attempt has been made to recommend, within each set, indicators which reflect a population, clinical, patient, and in relevant cases, a carer perspective.

Severe Mental Illness Working Group

1.6 The terms of reference and membership of the Group are shown in Appendix B. The Group included representatives of professional, managerial and service users’ groups involved with the prevention and treatment of severe mental illness.

1.7 The work of the Group had three main components:

- development of check lists including a health outcomes model for severe mental illness to assist members choose candidate indicators by which is meant potential indicators worth detailed consideration
Severe Mental Illness Outcome Indicators

- specification of candidate indicators
- recommendations about implementation and further development.

1.8 In this Report:

- the health outcome model is described in Section 2
- work commissioned about definitions is included in Appendix C
- Health of the Nation Outcome Scales are reproduced in Appendix D
- work commissioned to support the model is included in Appendix E
- check lists for choosing candidate indicators are outlined in Appendix F
- guidelines for specifying candidate indicators are described in Appendix G
- a review of indicators developed previously is in Appendix H
- candidate indicators chosen for specification are listed in Section 3
- candidate indicator specifications are included in Section 4
- details of the new mental health minimum data set are included in Appendix I
- recommendations about implementation and development are made in Section 5
- references to all sections and appendices are in Appendix J.

Recommendations

1.9 The recommendations made by the Group were categorised as those which:

- can be implemented generally throughout the NHS as there are systems available which can provide the requisite data
- could be implemented now where local circumstances allow, and more generally in the near future once expected developments are in place
- will not be possible to implement in the near future but, because of their desirability, they should be considered in the future development of clinical and management information systems
- require further work before a recommendation can be made.

1.10 The recommendations have been further categorised as to whether the requisite indicators should be available:

- routinely on a universal and continuous basis
- from periodic surveys and/or sampling, either at different points in time nationally or in geographical areas when there is a particular need or interest.
2. HEALTH OUTCOME MODEL FOR SEVERE MENTAL ILLNESS

Definition and scope of the work

2.1 Severe mental illness encompasses a wide range of human problems which require mental health services. It, rather than any individual clinical diagnosis, was chosen as the mental health topic in the health outcomes work because it:

- provides a population of service users which is more homogeneous than diagnostic groups in respect of clinical severity, social impairment, behaviour patterns and need
- allows commissioners and providers to give priority to those most in need of services
- will assist the monitoring of the Care Programme Approach (CPA).

2.2 There is currently no nationally endorsed definition of severe mental illness. The Group needed such a definition so that:

- there was common understanding of what was being discussed
- risk factors and interventions could be identified
- numerators and denominators could be specified for relevant indicators
- there was an agreed basis for commissioning research.

The major impetus to developing clear and agreed definitions of the condition was that it would not be possible to develop indicators which compared services or population without them.

2.3 The Group acknowledged that in considering the development of a definition of severe mental illness there are two distinct perspectives, that of the service users and secondly that of the service providers. To assist their deliberations the Group commissioned Dr. Lelliott to prepare a short summary of existing definitions. The results are shown in Appendix C and the work identified has been from a service provider perspective only.

2.4 With the assistance of the literature review an initial definition of severe mental illness from a provider viewpoint was developed. The Group then further commissioned Dr. Lelliott to conduct a short pilot study to test the criteria for:

- Face validity: do professionals from different disciplines find the criteria acceptable?
- Construct validity: do the criteria differentiate between groups of users which would be expected to contain different proportions with severe mental illness?
- Feasibility: are the criteria easy to apply?
- Redundancy: are all the criteria necessary to identify severe mental illness?
2.5 A brief description of the study is included in Appendix C. The work showed that the criteria were acceptable and feasible, at least when used by a restricted number of professionals, and that some of the criteria were redundant.

2.6 Following the pilot study the following provider based definition was agreed:

- There must be a mental disorder as designated by a mental health professional (psychiatrist, mental health nurse, clinical psychologist, occupational therapist or mental health social worker) AND EITHER

- There must have been a score of 4 (severe/very severe problem) on at least one, or a score of 3 (moderately severe problem) on at least two, of the HoNOS items 1-10 (excluding item 5 ‘physical illness or disability problems’) during the previous six months OR

- There must have been a significant level of service usage over the past five years as shown by:
  - a total of six months in a psychiatric ward or day hospital, or
  - three admissions to hospital or day hospital, or
  - six months of psychiatric community care involving more than one worker or the perceived need for such care if unavailable or refused.

Details of the Health of the Nation Outcome Scales (HoNOS) are outlined in Appendix D.

2.7 Consideration was given to the initial scope and whether any particular diagnosis, conditions or age groups should be excluded from the Group’s work to develop indicators. It was agreed in this phase of work not to include:

- people with dementia
- people with learning disability (unless with a co-existing mental illness)
- children and adolescents.

2.8 However, included in the work, if they meet the criteria, are people diagnosed with:

- mental and behavioural disorders due to psychoactive substance abuse
- schizophrenia, schizotypal and delusional disorders
- mood (affective) disorders
- neurotic, stress-related and somatoform disorders
- behavioural syndromes
- disorders of adult personality and behaviour.
2.9 The Group has developed a definition of severe mental illness which is an improvement on existing ones. However, our work and all that carried out previously has been solely from the provider perspective. Before a nationally agreed definition can be promulgated the Group considered it essential that work be commissioned to:

- develop a definition from the service user perspective including users from ethnic minority groups.
- see whether a unified definition including both perspectives can be agreed.

Developing a health outcome model

2.10 The health outcome model was developed as an aid to help Group members identify potential indicators. The model contains four elements:

- an overview of the epidemiology of severe mental illness
- a review of causes and risk factors
- a review of the course, complications and consequences of severe mental illness
- a review of relevant interventions.

2.11 The Group is indebted to Dr. Paul Lelliott for collating the information used in the outcome model and to Ms. Alison Eastwood for carrying out three commissioned literature reviews, related to severe mental illness, which are in Appendix E:

- long term outcomes
- cross-cultural outcomes
- organisation of services.

Overview of epidemiology

2.12 In the absence of widely recognised criteria, the epidemiology of severe mental illness has to be inferred from reviews of service use and from epidemiological surveys which rely on service use or diagnosis. The key information sources were:

- Department of Health returns on mental health service activity
- OPCS surveys (Meltzer et al. 1995a)
- Epidemiological catchment area surveys in the United States (Robins and Regier 1991)
- Mental health epidemiologically based needs assessment (Wing 1994i)
- Quinquennial survey of community psychiatric nurses (White 1990).
2.13 It has been estimated that about 6 per 1000 of the population have mental illness of a severity that warrants long-term care (Craig 1992; Conway et al. 1994a).

2.14 The concept of filters to care (Goldberg 1991) which recognises that people move between different levels of care is relevant when estimating the size of the population of people with severe mental illness. The following estimates have been made (Wing 1994) of the proportion of the general population receiving particular services who have a mental disorder:

- 26% of attenders in general practice have a mental disorder
- 1% of attenders in consultant out-patient clinics have a mental disorder
- 0.1% of in-patients have a mental disorder.

2.15 The great majority of those receiving in-patient care would have severe mental illness as would a high proportion of those attending out-patient services on a continuing basis. A small proportion of GP attenders would also meet the criteria; although one estimate suggests that 25% of people diagnosed as having schizophrenia are in contact with their GP only.

2.16 A survey of eight health districts found that 0.09% of the population were in supported non-hospital accommodation, designated specifically for people aged between 18 and 64 with mental illness. The great majority would have met the criteria for severe mental illness (Lelliott personal communication).

2.17 Admission rates are closely related to census variables, particularly poverty, social isolation and ethnicity (Glover et al. 1995; Jarman et al. 1984) and it is likely that the prevalence of severe mental illness has a similar relationship. Cross-cultural issues are discussed in Appendix E.

2.18 About £2 billion per annum is spent by the health and social services on specialist mental health services. It is likely that the bulk of this is for people who would meet criteria for severe mental illness. Despite the reduction in the number of hospital beds, about 75% of hospital and community health services expenditure on mental illness still goes to provide psychiatric in-patient care (Lelliott et al. 1993). It has been estimated that the lifetime costs of caring for a person diagnosed with severe schizophrenia may amount to over £300,000, with costs even higher for the most severely ill and disabled (Davies and Drummond 1994).

Causes and risk factors

2.19 Apart from certain forms of organic brain syndrome, some drug and alcohol related conditions and certain psychiatric conditions associated with physical illness, little is known about the precise causes of the disorders subsumed under severe mental illness. Individuals may be predisposed by genetic,
physical, physiological and social environmental factors. In the UK, associations with severe mental illness include:

- gender; all forms of depression are more common in women
- age; the incidence of severe depression increases with age
- marital status; there is a strong association between unmarried status and schizophrenia
- social environment
- childhood experience.

2.20 There is good evidence that there are triggers which can precipitate the onset of some forms of mental illness. These include:

- life events
- chemical agents, prescribed medications, alcohol and illicit drugs
- childbirth
- physical illness and head injury.

2.21 There are also factors that can either precipitate or protect against relapse in people whose mental illness is in remission:

- life events
- level of ‘expressed emotion’ in, and ‘face to face contact’ with, people with whom they are closely involved
- opportunities for work, occupation or recreation
- availability of effective interventions including social support.

Course, complications and consequences

2.22 Personality disorders are usually lifelong. With the exception of certain forms of paranoid psychosis and depression, the commonest age of onset of the other conditions subsumed under severe mental illness is early adulthood.

2.23 For people diagnosed with schizophrenia:

- about one third recover fully from a first episode with no need for long-term medication or other treatment
- about one third have repeated relapses but in between episodes function at a reasonable level, usually with the help of medication or other treatment and support
- about one third have severe persisting problems, only partially relieved by medication or other treatments.
2.24 Affective disorders and neurotic, stress related and somatoform disorders as well as behavioural syndromes vary greatly in their severity, course and extent of incapacity caused. The majority of people with these disorders would probably not meet the criteria for severe mental illness and have relatively brief episodes from which they recover. Those with more severe forms would meet the criteria, and a proportion of these would have episodic conditions which benefit from continuous treatment and care and a smaller proportion would have secondary handicaps resulting in chronic disablement. Long term outcomes are discussed more fully in Appendix E.

2.25 With respect to mortality (Conway et al. 1994a):

- the standardised mortality ratio of people with schizophrenia is about 2.5 times higher than the general population
- between 10% and 15% of people with schizophrenia and severe affective disorders commit suicide
- about 5% of people with personality disorders commit suicide and they have a higher death rate from accidents than the general population.

2.26 Children of parents with mental health problems are associated with an increased risk of child psychiatric disorder. In one study (AMA 1993) over half of the children with mild to severe behavioural problems had mothers who were significantly depressed, while this was the case in only 3% of children with no problems.

Relevant interventions

2.27 The Group reviewed the relevant interventions for severe mental illness using the following classification of types of interventions aimed to:

- reduce or avoid risk of severe mental illness
- detect severe mental illness early
- maintain function and reduce need for hospital admission
- restore function and reduce risk of relapse following hospital admission
- promote independent living and well-being
- sustain a collaborative approach between service providers, service users and their carers
- support carers and reduce the impact of severe mental illness on them
- ensure protection and good physical health of service users
- ensure protection of carers, service providers and the public.

2.28 There is little evidence that risk at population level can be reduced or avoided, although it might be possible using early detection to reduce the individual's risk by:

- targeting people with high family susceptibility
Severe Mental Illness Outcome Indicators

- targeting vulnerable groups such as homeless people, pregnant women and survivors of abuse in childhood
- improving detection rates in primary care
- targeting parents with severe mental illness to support their parenting and to ensure their children’s needs are met.

2.29 Theoretically the early detection and treatment of people with minor mental disorders could reduce the numbers progressing to the extent that they meet the criteria for severe mental illness. There are as yet major practical difficulties in all potential approaches to early detection because very many people experience minor mental disorders and the detection of those who will go on to meet the severe mental illness criteria is unreliable.

2.30 Interventions to maintain function and reduce the need for hospital admission might include:

- close observation and support which might involve admission to safe settings or intensive support in the community
- appropriate medication
- specific psychotherapies such as cognitive therapy for people with depression or behaviour therapy for phobic disorders
- electroconvulsive therapy for carefully selected patients with severe depression.

2.31 Interventions to restore function and reduce risk of relapse might include:

- medication such as anti-psychotics and anti-depressants
- specific psychotherapies such as family therapy for people diagnosed with schizophrenia
- psycho-educational interventions and strategies for self-management.

2.32 Interventions aimed to promote independent living and well-being might include:

- optimal use of medication
- long term care in supported accommodation
- specific techniques used in rehabilitation programmes
- care management of people living independently
- improved access to work and leisure opportunities in a safe environment
- meaningful daytime occupation
- welfare advice.

2.33 The current collaborative approach developed by the Department of Health for the long term community care of people with severe mental illness is the Care Programme Approach (CPA) and services organised in this way should include (NHS Executive 1996):
streamlined policies and procedures which ensure that the CPA process is carried out effectively
- appropriate management and funding processes
- integration between health and social services professionals and close liaison with the voluntary and private sectors
- the explicit targeting of resources on people with severe mental illness with tiering of the approach so that the most severely mentally ill receive the most intensive care
- information systems supporting the continuity of care
- well trained and appropriately chosen key workers.

2.34 The Care Programme Approach may be improved specifically for service users and carers, when appropriate, by:

- effective involvement in planning the service
- better information provision about the rationale and effects of interventions
- involvement in decisions about interventions and the offer of a choice where more than one alternative form of care is available
- involvement in the preparation of individual care plans
- adopting the service users’ view of a good outcome
- prompt and active follow-up of people who lose touch with services
- assertive outreach and listening to the needs of people who are difficult to engage with services
- advocacy and empowerment.

2.35 The delivery of care consistent with CPA to people in the community has not yet been proven to be more effective than ‘standard treatment’ and this issue is discussed more fully in Appendix E. However, there is evidence that intensive community treatment reduces admission rates and the time spent in hospital and that it is preferred by service users (Marshall, personal communication).

2.36 The interactions between people with severe mental illness and their informal carers is complex and based on mutual personal relationships which are different from the relationship between a service user and paid provider. Many people with severe mental illness live independently without a carer and some do not consent to receiving support from a self appointed carer. The Group whilst recognising the utility of the research to date considered that:

- the definitions of carer are still inadequate
- the use of the term burden is pejorative and fails to recognise the complex relationship between the carer and the individual with severe mental illness.
2.37 The impact on carers might be ameliorated by:

- assessment of their needs
- providing better information about psychiatric illness, treatments and services
- improving responsiveness of services to requests for help which might include identification of a named contact
- providing more, and more responsive, respite care.

2.38 To reduce the risk of service users harming themselves and others, close observation and support is sometimes required in appropriate settings and, when necessary, the use of legal powers available under the Mental Health Act. Risk assessment is now obligatory with the implementation of the Supervisory Register.
3. CHOICE OF CANDIDATE INDICATORS

3.1 To assist the Group choose the candidate indicators two literature reviews were commissioned and a matrix was developed to ensure the coverage of all relevant aspects of health outcomes.

3.2 The two literature reviews which were commissioned from the UK Clearing House on Health Outcomes are shown in Appendix H.

Outcomes matrix

3.3 To ensure that all potentially useful aspects of outcomes were considered the matrix in Exhibit 1 was drawn up using the following dimensions:

- aims of interventions (see paragraph 2.27)
- perspectives of measurement (see paragraph F7).

**EXHIBIT 1: MATRIX FOR OUTCOME INDICATORS FOR SEVERE MENTAL ILLNESS**

<table>
<thead>
<tr>
<th>Aim of intervention</th>
<th>Primary measurement perspective</th>
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<tbody>
<tr>
<td>Reduc e or avoid risk of SMI</td>
<td>Population 1</td>
</tr>
<tr>
<td>Detect SMI early</td>
<td>Clinical 2</td>
</tr>
<tr>
<td>Maintain function and reduce need for hospital admission</td>
<td>User 3, 4, 5, 6</td>
</tr>
<tr>
<td>Restore function and reduce risk of relapse following hospital admission</td>
<td>Carer 8, 7</td>
</tr>
<tr>
<td>Promote independent living and well-being</td>
<td>Population 11, 12, 13, 10, 9</td>
</tr>
<tr>
<td>Sustain a collaborative approach between service providers, service users and their carers</td>
<td>15, 14</td>
</tr>
<tr>
<td>Support carers and reduce the impact of SMI on them</td>
<td>16</td>
</tr>
<tr>
<td>Ensure protection and good physical health of service users</td>
<td>Population 17, 18</td>
</tr>
<tr>
<td>Ensure protection of carers, service providers and the public</td>
<td>19, 20</td>
</tr>
</tbody>
</table>
3.4 For each part of the matrix consideration was given to possible indicators. Using the information in the health outcome model, candidate indicators were identified as shown in the paragraphs which follow. The numbers in the text relate to Exhibit 1 and to the indicator specifications in the next Section.

3.5 In view of the lack of evidence about interventions to reduce the risk of the condition or to detect it early, only two candidate indicators were specified with respect to these intervention aims:

1: prevalence of SMI
2: in-patient admission on detection of SMI.

3.6 Four candidate indicators were specified which related to the maintenance of function:

3: HoNOS scores for a service provider population of people with SMI
4: proportion of people with SMI lost to follow-up by specialist services
5: proportion of people with SMI discharged from follow-up by specialist services
6: proportion of people with SMI spending more than 90 days in a given year in in-patient psychiatric care.

3.7 With respect to restoring function and reducing risk of relapse two candidate indicators were specified:

7: longitudinal indicators of change in item, subscale and total HoNOS scores among people with SMI admitted to in-patient psychiatric care
8: hospital re-admission frequencies for a resident population of people with SMI.

3.8 The promotion of independent living and well-being has many facets and important factors identified by the Group were employment, financial status, accommodation and lack of side-effects from drug therapy. Five candidate indicators were specified:

9: user-assessed health-related quality of life for a service-provider population of people with SMI
10: prevalence of side-effects associated with maintenance neuroleptics within a service provider population of people with SMI
11: paid employment status of people with SMI
12: financial status of people with SMI
13: accommodation status of people with SMI.
3.9 The Care Programme Approach emphasises the need for a **collaborative approach** and two candidate indicators were specified related to this aim:

- **14**: summary of a measure of user satisfaction with respect to a specific mental health service, among people with SMI
- **15**: percentage of CPA care plans for people with SMI signed by the users.

3.10 One indicator has been specified with respect to the **impact on carers**:

- **16**: assessment of impact of SMI on carers.

3.11 Two indicators have been specified with respect to the **service users’ protection and good physical health**:

- **17**: mortality among people with SMI
- **18**: use of non-psychiatric health care services by people with SMI.

3.12 The **protection of carers, service providers and the public** has been covered by two candidate indicators which have been specified:

- **19**: number of homicides by people with SMI
- **20**: incidence of serious physical injury resulting from assaults on staff and service users by people with SMI.
Severe Mental Illness Outcome Indicators
4. CANDIDATE INDICATOR SPECIFICATIONS

4.1 This Section contains the detailed specifications of the candidate indicators chosen by the Group. They have been grouped together by the types of health intervention as shown in Exhibit 1.

4.2 Guidance notes which explain the attributes used in the specifications are included in Appendix G.

4.3 The detailed work of the specifications was carried out by Robert Cleary and James Coles of CASPE Research with assistance from Ewan Wilkinson of the Unit of Health-Care Epidemiology, University of Oxford.

4.4 Reference is made in many of the specifications to the mental health minimum data set. Appendix I includes details about the new proposals.
Severe Mental Illness Outcome Indicators

**Candidate indicator 1**

<table>
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<td>Cross-sectional</td>
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<tr>
<td>Outcome relationship</td>
<td>Direct</td>
</tr>
</tbody>
</table>

**Title**  Prevalence of SMI

**Intervention aim** Reduce or avoid risk of SMI.

**Definition** For a given resident population and year: the number of people meeting the operational definition of SMI (see below), divided by the size of the resident population.

**Definition of SMI**
- There must be a mental disorder as designated by a mental health professional (psychiatrist, mental health nurse, clinical psychologist, occupational therapist, mental health social worker) AND EITHER
- There must have been a score of 4 (severe/very severe problem) on at least one, or a score of 3 (moderately severe problem) on at least two, of the HoNOS items 1-10 (excluding item 5 ‘physical illness or disability problems’) during the previous six months OR
- There must have been a significant level of service usage over the past five years as shown by:
  - a total of six months in a psychiatric ward or day hospital, or
  - three admissions to hospital or day hospital, or
  - six months of psychiatric community care involving more than one worker, or the perceived need for such care if unavailable or refused.

The rate should be reported as crude, age standardised, and age, sex and ethnic origin specific rates.

**Rationale** It may be possible to prevent some mental illness from progressing to SMI. The prevalence of SMI in the overall population will in part reflect any failure to prevent this progression.

**Potential uses** Assessment of regional/national trends or progress towards targets; population based comparisons; planning of local clinical services.

**Potential users** Commissioners, clinicians.

**Possible confounders** The operational definition requires a diagnosis, a HoNOS score and some period of contact with the mental health services. This definition therefore excludes people who have never been in contact with mental health services. People who are homeless, for example, are less likely to be in contact with health services and therefore the incidence rate for this group is likely to be underestimated. The inclusion of a service use component in the definition will also mean that differences in service provision, perhaps influencing thresholds for hospital admission, will affect the apparent prevalence.
Data sources

This information is not routinely available on a district basis. On a national basis the ONS surveys of psychiatric morbidity include data from those living in private households (Meltzer et al. 1995a), those living in institutions for people with mental illness (Meltzer et al. 1996) and the homeless (Gill et al. 1996), but a different definition of SMI is used.

While current contract minimum data sets (CMDSs) detail some of the service use components of the definition (as well as the diagnostic component), they do not capture the required HoNOS or community care data, and so the definition cannot be met from current routine sources.

The proposed mental health minimum data set (MHMDS; see Appendix I) would in theory provide all the data elements required for this indicator, except that while details of the community care received are included in the data set, the unmet need for such care is not captured. A practical limitation also applies in that the definition’s retrospective view of service use over a five year period means that the MHMDS could not be the sole source of data for identifying people with SMI until five years’ worth of historical data had been amassed.

In the short term the most practical option for data collection will be periodic surveys at the level of individual providers, drawing on clinical case notes, CPA records and, in time, information systems put in place to support the MHMDS.

Data quality

Development plans for the proposed MHMDS include pilot testing which will include assessments of data quality. Field trials of the HoNOS component of the data set have demonstrated acceptable levels of reliability (Wing et al. 1996).

Where the indicator is estimated on the basis of a sample-based survey of clinical records, the validity of the result may be particularly dependent on the completeness of those records with respect the use of psychiatric hospital over the previous five years.

Comments

The value of this indicator would be enhanced by reporting the prevalence for a variety of subgroups - for example those in prisons, the homeless - as well as for ethnic minorities. However, simple breakdowns of the general rate may misrepresent the prevalence within such groups. It is likely that different specialised methods for each subgroup will be required to supplement the routine monitoring for the general population.

Once routine monitoring of prevalence is established, and experience in its interpretation has been obtained, it may be appropriate to develop one or more incidence based indicators based on the same definition of SMI.

Further work required

Development of additional methods for monitoring prevalence in subpopulations.
Conclusion & priority

Initially: A. To be implemented generally by periodic survey.
In the longer term: C. To be implemented following development of information systems on a routine basis.

References


Candidate indicator 2

Title

In-patient admission on detection of SMI

Intervention aim

Detect SMI early.

Definition

For a given resident population and year: the number of people meeting the diagnostic and HoNOS criteria for SMI (see Indicator 1) whose first contact with the mental health services coincides with an in-patient psychiatric admission occurring within the given year, divided by the total number of people meeting the diagnostic and HoNOS criteria for SMI presenting for the first time to the mental health services, in the given year. The resulting fraction should be reported with its associated numerator, by age group, sex and ethnic origin.

A 'first' contact or presentation is defined as one where the individual has not had any contact with mental health services during the previous five years.

Rationale

If SMI is detected in a person before a crisis point is reached, treatment may be provided within the community and it may be possible to avoid an in-patient admission. If the first contact with the mental health services coincides with an in-patient admission it may suggest that early signs of severe mental illness were not detected. With this in mind, this indicator is proposed as a measure of the effectiveness of early detection processes.

Potential uses

Assessment of regional/national trends or progress towards targets; population based comparisons; clinical audit.

Potential users

Commissioners, clinicians.

Possible confounders

Levels of in-patient service provision may influence admission thresholds.

Data sources

Current routine data sources do not support the collection of this indicator - in particular, HoNOS measures and records of community interventions are not covered by current CMDSs. The proposed MHMDS (see Appendix I) would allow first contacts to be identified once a comprehensive historical database (offering at least five years’ coverage) was established. However, the proposed data set would not support the identification of the subset of first contacts for which an immediate in-patient admission was made. To do this, the underlying records of in-patient episodes – from which the relevant portion of the MHMDS would be derived – would have to be examined.

In advance of widespread MHMDS implementation, calculation of this indicator would be best achieved by auditing a sample of cases newly referred to specialist services. Where HoNOS data are not collected routinely, these assessments would have to be incorporated within the audit protocol.
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Data quality

Development plans for the proposed MHMDS include pilot testing which will include assessments of data quality.

Comments

‘Early detection’ was identified by the Working Group as an important aim of care for people with SMI. This indicator attempts to operationalise a measure of early detection. However, in advance of pilot testing the definition the interpretability and utility of this indicator is unclear.

Further work required

Pilot testing of MHMDS.

Conclusion & priority

D. To be further developed because link with effectiveness is unclear and indicator specification is not complete.

References

None.
**Candidate indicator 3**

<table>
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<td><strong>Timeframe:</strong></td>
<td>Cross-sectional</td>
</tr>
<tr>
<td><strong>Outcome relationship:</strong></td>
<td>Direct</td>
</tr>
</tbody>
</table>

**Title**

HoNOS scores for a service provider population of people with SMI

**Intervention aim**

Maintain function and reduce need for hospital admission.

**Definition**

For a given mental health service provider and year: the median and inter-quartile ranges of subscale and total HoNOS scores, together with the distribution of each item score, as assessed by the provider during the given year, for the population of people with SMI included in the provider’s caseload at any point in the year. Where an individual service user has had more than one HoNOS assessment within the given year, only the worst score obtained is included in the aggregation.

Item scores should be reported as a percentage-based distribution across their underlying range of 0-4. Subscale and total scores should be normalised to a 0-100 range. The size of the provider’s cumulative caseload for the year should also be reported, along with the number of people within that caseload who received at least one HoNOS assessment during the year. In addition to being reported for the whole caseload, the statistics should be broken down by primary diagnosis (at the level of ICD-10 two-character code) and, within diagnosis, by age, sex and ethnic origin. Diagnostic categories accounting for less than 5% of cases may be collapsed into an ‘other’ category.

**Rationale**

The Health of the Nation Outcome Scales (Wing et al. 1996) are designed to record a concise clinical assessment of the severity of a range of health and social problems likely to be experienced by people with SMI. The 12-item assessment is divided between four dimensions (termed ‘behaviour’, ‘impairment’, ‘symptoms’ and ‘social problems’), each of which yields a subscale score. The summation of these four scores yields a total score. While use of the scales is not yet widespread, they have undergone encouraging field trials and are the focus of a training and implementation programme within the NHS.

The breadth and multi-dimensional nature of the assessment makes it relevant to a number of the intervention aims identified by the health outcome model for SMI. For example, the success of broad aims relating to the maintenance of function are likely to be reflected in levels of severity across subscales. The reporting of an individual subscale, such as ‘social problems’ (covering problems with living conditions, daily activities and relationships), allows a focus on the aim of promoting independent living. Scores for individual items (e.g. ‘suicidal thoughts and non-accidental self-injury) provide specific information relevant to some of the other intervention aims (e.g. ensure protection and good physical health of service users).

The indicator provides a cross-sectional view of a service user population rather than relating a longitudinal assessment to a specific intervention. As such, its value is likely to be seen in comparisons between providers serving similar populations, or in the analyses of population-level trends over time. The lack of a focus on a particular intervention makes the indicator suitable for a range of service providers -
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Community, residential, institutional - and perhaps particularly appropriate for use in a continuing, as opposed to acute, care-setting.

**Potential uses**
Provider-based audit; comparisons between providers and over time; assessments of regional/national trends or progress towards targets.

**Potential users**
Providers, commissioners, regional/national policy makers.

**Possible confounders**
A wide range of case-mix factors that are likely to be correlated with severity of problems suffered by people with SMI may be confounded with any inter-provider or time trend comparison. In addition to the age, sex and diagnosis variables incorporated in the definition, the associations of HoNOS with pre-onset social and role performance have been highlighted (Wing et al. 1996).

In general, the severity of problems experienced by the population of users of a particular service is likely to be highly dependent on the severity presented to the service on referral. Any comparisons of this indicator (across time or providers), that aim to question relative effectiveness, should be informed by knowledge of this baseline severity.

**Data sources**
The HoNOS Raters’ Pack (Royal College of Psychiatrists 1996) provides a standard pro-forma and glossary for the recording of HoNOS assessments, together with a range of relevant case-mix variables. The pack could be used as the basis for a locally established system of routine HoNOS assessment.

The proposed mental health minimum data set (MHMDS; see Appendix I) provides a standard data set specification and central return mechanism which includes details of the HoNOS scores obtained within a given three month (or one year) reporting period. However, while the current data set specification includes the best HoNOS score obtained within a reporting period, a small modification would be required to include a corresponding item for the worst obtained during the same interval. The MHMDS would also support the identification of the year’s caseload and (subject to the caveats given for Indicator 1) the subset of those cases meeting the operational definition of SMI.

In the absence of this centrally defined data set, local provision would have to be made for the aggregation and reporting of HoNOS data. Under these circumstances, the identification of cases meeting the operational definition of SMI will require the examination of case notes and other clinical records.

**Data quality**
Field trials of HoNOS have demonstrated acceptable levels of reliability and sensitivity to clinical change (Wing et al. 1996). More detailed experimental assessments of reliability and validity are underway but have yet to be reported. Experience from the field trials to date has underlined the importance of training in obtaining valid and reliable assessments.
Development plans for the proposed MHMDS include pilot testing which will include assessments of data quality.

Comments
As noted above, interpretation of this indicator might be aided by a parallel consideration of HoNOS scores at referral. The process of data collation and analysis specified here could be extended to yield a second indicator, characterising the severity of problems experienced by service users at the time of their initial assessment.

Although the general cross-sectional measure specified for this indicator makes it applicable to a range of continuing care settings, longitudinal indicators of severity would also be of value in monitoring the care provided for people with chronic problems. Given that a simple ‘before and after’ model of measurement would not be appropriate, the Group considered some alternatives. For example, current severity for an individual might be related to some measure of their previous best or a personal norm. The general literature on statistical process control techniques might be useful in defining such indicators. However, it was felt that further experience of collecting and reviewing cross-sectional severity data should be gained before more sophisticated derived measures were specified.

Further work required
None recommended

Conclusion & priority
Initially: B. To be implemented where local circumstances allow by periodic survey.
In the longer term: C. To be implemented following development of information systems on a routine basis.

References

**Candidate indicator 4**

**Title**
Transform function and reduce need for hospital admission.

**Definition**
For a given provider and year: the number of people with SMI whose contact with the provider has lapsed within the given year, divided by the number of people with SMI under the care of the given provider at any point during the given year. The resulting fraction should be expressed as a percentage and reported with its associated numerators by age-group, ethnic origin and sex.

A person's contact with the provider is defined as having lapsed where:

- they have been out of contact with the provider for a period of at least three months following a failure to attend a planned contact (for which the appointment fell within the reporting year); or
- they have been discharged from care against professional advice in the course of the reporting year.

**Rationale**
The Care Programme Approach (CPA; Department of Health 1990; Department of Health 1995) has formalised the organisation of care for people with a mental illness and follow-up appointments are recognised as an important aspect of the approach. The NHSE’s audit pack for monitoring the CPA, developed by the Royal College of Psychiatrists’ Research Unit (National Health Service Executive 1996) identifies losses to follow-up as an important indicator of CPA outcomes. The pack’s authors reason that where the Approach is successful in encouraging more people with SMI to remain in contact with services, this should help reduce rates of relapse and re-admission to hospital.

**Potential uses**
Management of clinical services, provider based comparisons, clinical audit.

**Potential users**
Clinicians, commissioners, provider management.

**Possible confounders**
Variations between providers in the frequency of planned contact with users may influence the proportion of cases identified as lost to follow-up.

**Data sources**
Under the Care Programme Approach each contact with a service user should be recorded, along with planned subsequent contacts. However, the collation of these data, in order to calculate the indicator specified here, is likely to be problematic unless all relevant records are computerised. While such information systems are being put in place to support the CPA, it may be appropriate to restrict this indicator to the subset of people with severe mental illness who are also on the supervision register (Department of Health 1994). This focus would both reduce the scale of data collection required, and direct attention towards losses to follow-up among those for whom follow-up is judged to be particularly important.
Data quality
The validity of this indicator will be critically dependent on the completeness and availability of relevant CPA records. It is likely that details of actual and planned care contacts will be tolerably well recorded in supervision register cases.

Comments
Users who do not keep in contact with specialist services may choose to do so on the basis that they judge they are well enough not to need the contact.

Further work required
As specified here the indicator uses a period of three months to define lapsed contact. The use of other intervals may be appropriate, and the effect of this variable should be examined in pilot testing of the indicator.

Conclusion & priority
Initially, for people on the supervision register: B. To be implemented where local circumstances allow by periodic survey.
In the longer term, for all people with SMI: C. To be implemented following development of information systems on a routine basis.

References


Candidate indicator 5

<table>
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**Title**

Proportion of people with SMI discharged from follow-up by specialist services

**Intervention aim**

Maintain function and reduce need for hospital admission.

**Definition**

This specification relies on the definition of a mental health care spell (MHCS) incorporated in the proposals for a mental health minimum data set (MHMDS) described in Appendix I. An MHCS is defined as the total period during which a person receives care from mental health specialist staff, beginning with the first face to face contact and finishing with a discharge which may be either in accord, or against, professional advice.

For the purposes of the indicator defined here a related concept is defined: an ‘SMI care spell’ is an MHCS associated with a person who has met the criteria of the operational definition of SMI (see Indicator 1) at any point during that MHCS.

For a given provider and year: *the number of SMI care spells ending within the given year as a ‘discharge in accord with professional advice’, divided by the number of SMI care spells falling (either wholly or partly) within the given year.*

The resulting fraction should be expressed as a percentage and reported with its associated numerator by age-group, ethnic origin and sex.

**Rationale**

For people having suffered SMI, discharge from specialist care is assumed here to be a proxy for recovery. One outcome of the care provided for those with SMI is a reduction in the severity of the illness to a point where specialist services are no longer required. This indicator will identify the proportion of cases in which that outcome is obtained.

**Potential uses**

Management of clinical services, provider based comparisons, clinical audit.

**Potential users**

Clinicians, commissioners, provider management.

**Possible confounders**

Variations between providers in discharge thresholds will influence this indicator.

**Data sources**

This activity-based measure could be readily calculated following the implementation of a standard data collection along the lines of the MHMDS, described in Appendix I.

In the absence of comprehensive routine data collection, calculating the indicator would still be possible if, historically, HoNOS assessments had been made and recorded routinely. The numerator could be estimated from a survey of discharges which was aimed at identifying those individuals who had met the criteria for SMI while they were under the care of the provider. The required denominator could be similarly estimated on the basis of a survey of clinical records – in this case the sample would be drawn from the overall current case load.
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<th><strong>Data quality</strong></th>
<th>The basic facts of a discharge, including its status with respect to professional advice are likely to be well recorded. The comments regarding MHMDS data quality noted in Indicator 1 apply here also.</th>
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<td><strong>Comments</strong></td>
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<td><strong>Further work required</strong></td>
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| **Conclusion & priority** | **Initially**: B. To be implemented where local circumstances allow by periodic survey.  
**In the longer term**: C. To be implemented following development of information systems on a routine basis. |
| **References**   | None. |
**Candidate indicator 6**

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**Title**
Proportion of people with SMI spending more than 90 days in a given year in in-patient psychiatric care

**Intervention aim**
Maintain function and reduce need for hospital admission.

**Definition**
For a given resident population and year: the number of people with SMI who have spent more than 90 days of the given year in in-patient psychiatric care (at any unit), divided by the number of people with SMI. The resulting fraction should be expressed as a percentage and reported with its associated numerator as an overall figure and by age-group, ethnic origin and sex.

**Rationale**
Maintaining people with SMI in the community is generally desirable. However, relatively brief admissions to in-patient care may be part of appropriate care in pursuit of this goal in the longer term. In focusing on those patients who experience cumulatively long periods of in-patient care this indicator reflects the proportion of cases for which care in the community is relatively ineffective.

**Potential uses**
Clinical audit, management of clinical services, provider based comparisons.

**Potential users**
Clinicians, commissioners, provider management.

**Possible confounders**
Levels of in-patient service provision may influence admission and discharge thresholds.

**Data sources**
The proposed minimum data set for mental health care (see Appendix I) will support this indicator, including, subject to the caveats given for Indicator 1, the identification of the population suffering from SMI.

**Data quality**
Development plans for the proposed minimum data set for mental health care include pilot testing which will include assessments of data quality.

**Comments**
None.

**Further work required**
None recommended.

**Conclusion & priority**
C. To be implemented following IT development on a routine basis.

**References**
None.
**Candidate indicator 7**

**Title**  
Longitudinal indicators of change in item, subscale & total HoNOS scores among people with SMI admitted to in-patient psychiatric care  
a) Mean change in HoNOS scores, as measured on admission and discharge, within an in-patient population of people with SMI.  
b) Mean change in HoNOS scores, as measured on admission and at 90 days post admission, within an in-patient population of people with SMI.

**Intervention aim**  
Restore function and reduce risk of relapse following hospital admission.

**Definition**  
For a given follow-up assessment, year and population of people with SMI discharged within the given year from a given in-patient psychiatric provider: (1) the mean differences (with associated standard deviations) in individuals' item, subscale and total HoNOS scores, from an admission baseline to a follow-up assessment; and (2) the mean and standard deviation of the baseline scores.  
Item scores should be reported within their underlying range of 0-4. Subscale and total scores should be normalised to a 0-100 range. The number of discharges in the year should also be reported, along with the numbers of discharges who received (1) a baseline assessment, (2) a follow-up assessment, and (3) both. In addition to being reported for all discharges, the statistics should be broken down by primary diagnosis (at the level of ICD-10 two-character code) and, within diagnosis, by age and sex.

An ‘admission baseline’ refers to an assessment of symptom severity made within 24 hours of admission. A ‘follow-up assessment’ refers to a comparable severity assessment made either within the 24 hours prior to discharge (Indicator a) or at 90 days post-admission (± 30 days) (Indicator b).

**Rationale**  
The Health of the Nation Outcome Scales (HoNOS; Wing et al. 1996) are designed to record a concise clinical assessment of the severity of a range of health and social problems often experienced by people with SMI (see also Indicator 4). Following admission to hospital, achievement of the aims of ‘restored function’ and ‘reduced risk of relapse’ specified by the health outcome model is likely to be reflected in a reduction in the severity of these problems. The indicators specified here provide a clinical assessment of the reduction in severity that has been achieved, and maintained in the short term.

**Potential uses**  
Provider-based audit; comparisons between providers and over time; assessments of regional/national trends or progress towards targets.

**Potential users**  
Providers, commissioners, regional/national policy makers.
**Possible confounders**

A wide range of case-mix factors that are likely to be correlated with severity of problems suffered by people with SMI may be confounded with any inter-provider or time trend comparison. In addition to the age, sex and diagnosis variables incorporated in the definition, the associations of HoNOS with pre-onset social and role performance have been highlighted (Wing et al. 1996).

**Data sources**

Although the clinical assessment of health and social problems will be a normal component of admission procedures, discharge planning and follow-up for people admitted to in-patient psychiatric care, there is currently no widespread system for the routine collection of HoNOS severity data. The HoNOS Raters’ Pack (Royal College of Psychiatrists 1996) provides a standard pro-forma and glossary for the recording of HoNOS assessments, together with a range of relevant case-mix variables. The pack could be used as the basis for a locally established system of routine HoNOS assessment.

While local systems may readily support the collection of admission and discharge assessments, the logistics of capturing and collating follow-up assessments (which may occur in a wide range of settings) are likely to be more problematic. While the proposed for mental health minimum data set (MHMDS; see Appendix I) provides a central collation mechanism for relevant data, including HoNOS item scores, they are aggregated with respect to a three month ‘reporting period’.

In practice, it is likely that the feasibility of this indicator will depend on the development of the information systems to collect the detailed Care Programme Approach data, including HoNOS scores, which are then summarised within the MHMDS.

**Data quality**

Field trials of HoNOS have demonstrated acceptable levels of reliability and sensitivity to clinical change (Wing et al. 1996). More detailed experimental assessments of reliability and validity are underway but have yet to be reported. Experience from the field trials to date has underlined the importance of training for raters in obtaining valid and reliable assessments.

**Comments**

A range of indicators based on other follow-up periods may be defined along similar lines.

While the indicator definition currently specifies reporting of the mean (and standard deviation) of the observed change in scores, percentile-based statistics may prove more appropriate if the distribution of those changes are not normal.

**Further work required**

None recommended.

**Conclusion & priority**

C. To be implemented following IT development on a routine basis.
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References


Candidate indicator 8

Title
Hospital re-admission frequencies for a resident population of people with SMI

Intervention aim
Restore function and reduce risk of relapse following hospital admission.

Definition
For a given resident population and index year: the proportion of people with SMI who, having been admitted to in-patient psychiatric care in the index year are, within the 12 months following their index admission:
- not admitted again (to any unit)
- re-admitted once only
- re-admitted twice
- re-admitted three times or more.

In each case, the denominator is the total number of people in the resident population who have met the criteria for SMI at any point in the index year and the fraction should be expressed as a percentage and reported with its numerator. Statistics should be presented both for the whole population and broken down by ICD-10 two-character code, based on the primary diagnosis associated with their most recent assessment. Diagnostic categories accounting for less than 5% of the population figure may be collapsed into an ‘other’ category. Additional breakdowns by age, sex and ethnic origin should also be made available.

Rationale
The health outcome model for SMI includes a reduction in the ‘risk of relapse, following a hospital admission’ as one goal of care for people with SMI. While a series of admissions in relatively quick succession may be good and appropriate care for some patients, an unusually high rate of frequent re-admissions may also indicate high levels of relapse. By six months post-discharge re-admission rates may reach 20% or more, with substantial annual differences observable at the district level (Audit Commission 1994). Rates are also associated with a wide variety of user and service variables (Kent and Yellowlees 1994; Postrado and Lehman 1995; Thornicroft et al. 1992) and they have been identified as a useful indication of the effectiveness of post-discharge support and intervention (Jenkins 1990; Audit Commission 1994). Rates are also likely to be influenced by the effectiveness of the index episode of in-patient care - there is, for example, some limited evidence that reduced lengths of stay are associated with higher short term re-admission rates (Appleby et al. 1993).

Potential uses
Population based comparisons.

Potential users
Commissioners, clinicians, provider management, national/local policy makers.
The specified reporting by diagnostic category will act as a crude proxy for a range of patient characteristics associated with re-admission rates, however, severity information (such as that available from the HoNOS data yielded by Indicators 3 and 7) may enhance the interpretability of the indicator. The extent to which this approach captures the effect of specific co-morbidities which have been shown to influence re-admission rates such as alcohol or drug dependence (Caan and Crowe 1994) should be examined once data are available.

Possible confounders

Social factors reflecting the user’s post-discharge environment can be expected to influence the task facing community services seeking to prevent the relapse of users. Again, Indicators 3 and 7 provide some relevant data on accommodation etc.. At a population level consideration of deprivation indices may be useful, although this variable has had little impact in some previous analyses of inter-district variation in rates (Audit Commission 1994).

As the indicator uses secondary care activity as a proxy for relapse, it may be distorted by the shifting balance between community and in-patient provision. Where in-patient provision is relatively high, re-admissions may include more stays associated with social and respite reasons not indicative of relapse. Where there is a shift away from in-patient provision, fewer relevant relapses may lead to a hospital stay. While this indicator should be considered in the light of information on local service provision, it is worth noting that the Audit Commission (1995) found high re-admission rates co-existing with apparently under-used community facilities, and in the U.S. at least, some authors have given examples of wide variations in resources having little influence on re-admission, relative to that accounted for by case-mix variables (Fisher et al. 1992).

Data sources

In general, population-based re-admission indicators may be calculated using the current CMDS on in-patient activity in specialties 710-715 held by the commissioner for their residents.

This general guidance, however, will only go as far as identifying psychiatric admissions and re-admissions - it does not exclude those cases failing to meet the operational definition of SMI at the time of the index admission. Current contract minimum data does not hold the HoNOS or community service-use data required to do this. An enhanced data set, along the lines of the proposed mental health minimum data set (MHMDS; see Appendix I), would provide the necessary severity data. These could be linked (most readily once the NHS number is routinely available) with the CMDS data on individual admissions and discharges to calculate the required indicator rates.

Data quality

The validity of re-admission indicators based on the contract minimum data set will depend on the completeness of the data (i.e. all admissions must be recorded along with their associated specialty) and the accuracy of fields used for record linkage (patient identifiers and admission dates). These aspects of data quality may vary widely between provider units.
The development plans for the proposed mental health minimum data set include piloting which will include assessments of data quality.

Comments
None.

Further work required
None recommended.

Conclusion & priority
C. To be implemented following IT development on a routine basis.

References


Candidate indicator 9

Title
User-assessed health-related quality of life for a service-provider population of people with SMI

Intervention aim
Promote independent living and well-being.

Definition
The proposed approach to quality of life assessment is exemplified by the interview-administered Lancashire Quality of Life Profile (LQOLP; Oliver et al. 1996). The LQOLP covers nine life domains: work; leisure/participation; religion; finances; living situation; legal/safety; family relations; social relations; health.

Each domain is addressed by a small set of ‘objective’ indicators combined with a series of subjective ratings made using a seven-point Life Satisfaction Scale (LSS), adapted from the work of Andrews and Withey (1976). For example in the legal/safety domain the following questions are posed:

- **In the past year:**
  - Have you been accused of a crime?
  - Have you been assaulted, beaten, molested or otherwise a victim of violence?
  - Have there been any times when you would have liked police or legal help but were unable to get it?

- **How satisfied are you with:**
  - your general personal safety?
  - the safety of your neighbourhood?

For the first three objective items, simple yes/no/don’t know responses are recorded. For the pair of subjective ratings, responses are recorded using the LSS (couldn’t be worse; displeased; mostly dissatisfied; mixed feelings; mostly satisfied; pleased; couldn’t be better) with an index of satisfaction (averaged across the two ratings) between one and seven being reported for the domain.

For the population of people with SMI making use of a given mental health service in a given survey period the indicator requires, for each of the nine life domains, the reporting of: the mean LSS score (with associated standard deviation) together with the response distributions for each of the objective items. In addition to being reported for all respondents, the statistics should be broken down by primary diagnosis (at the level of ICD-10 two-character code) and, within diagnosis, by age and sex. The number of respondents, the number approached but declining to respond, and (where relevant) details of the sampling strategy used should be similarly reported.

Rationale
SMI can adversely affect the quality of an individual’s life directly, through the experience of the symptoms of mental distress, and indirectly, mediated by the impact of SMI on social circumstances or by the experience of health service interventions. Due to this wide range of potential effects, a broadly-based measure of quality of life is considered a vital component of any evaluation of attempts to ‘promote independent living and well-being’, as specified by the health outcome

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model for SMI. Due to the subjective nature of some of the required judgements, and potentially inadequate access of clinical assessors to some objective aspects of the lives of those with SMI, the set of indicators should include a users’ assessment of the quality of their lives.

An ideal quality of life indicator would probably be based on an instrument of sufficient brevity (and perhaps suitable for self-completion by the user) to make it suitable for routine administration. However, as the review by Andrews et al. (1994) - discussed in Appendix H of this document - makes clear, no such instruments are sufficiently well tested to be recommended at this stage.

However, mental health is an area in which particularly good progress has been made in developing tools to assess quality of life (Bowling 1995). In a review of this progress, Bowling discusses a number of lengthier interview-administered instruments that address broad conceptions of quality of life and are supported by evidence of acceptable psychometric properties. Of these, the Lehman et al. (1982) Quality of Life Interview is identified as the best on a range of criteria and, in the U.S., the most widely-used. The LQOLP, described in detail above, is a British adaptation of the Lehman instrument, has an extensive track record of testing in a variety of UK mental health settings (summarised by Oliver et al. 1996) and is judged by Bowling’s review to be one of the best developed British scales.

The LQOLP interview typically takes 30-40 minutes, which, while unlikely to be practical on a routine basis, may be justifiable for a sample-based survey within a population which has long-term needs for relatively extensive intervention.

The length of the instrument - around 80 items across the nine domains - allows the LQOLP to overcome some of the limitations of indicators that are purely objective (the selected items may not reflect the values of the individual) or purely subjective (individuals’ expectations may adapt to their objective circumstances) by using both approaches in tandem. While the interpretation of the resulting data across nine domains is unlikely to be straightforward, a cross-sectional indicator based on the LQOLP is proposed as a rich source of information for use in programme evaluation. The value of the indicator will be enhanced where normative data from comparable care settings, and the general population, are available.

**Potential uses**
Clinical audit, provider-based comparisons, assessment of regional/national trends.

**Potential users**
Clinicians, provider management, commissioners, national/local policy makers.

**Possible confounders**
A wide range of socio-demographic and clinical variables (e.g. diagnosis, duration of SMI) are likely to influence the results of comparisons based quality of life data.
Data sources

LQOLP interview following the protocol given in Oliver et al. (1996).

Data quality

As with any lengthy interview the LQOLP may be subject to significant levels of non-response. A 15% refusal rate in a sample of 80 service users diagnosed as psychotic was found by Huxley and Warner (1992). The exclusion from interviews of those people with SMI who have hearing or cognitive disabilities, or who are not English speaking, may also have a systematic effect on aggregate quality of life data.

Comments

With respect to the quality of life of people with SMI, there is insufficient evidence to judge any one measurement instrument as clearly the best in all respects. However, the LQOLP’s combination of objective indicators and subjective ratings represents an approach to measurement which is endorsed by the Working Group. The Group has also noted the wide range of on-going studies and audits employing the LQOLP, as evidenced by the LQOLP conference sponsored by the NHSE in June 1997.

The Quality of Life Schedule QLS (Barry and Crosby 1993) is an alternative UK adaptation of the original Lehman instrument. While experience with the LQOLP has encompassed a wider range of service settings, the Crosby measure also has an encouraging track record to date. The rationale given above for the use of the LQOLP is generally applicable to the QLS also, and selection between these two instruments may be best guided by local considerations.

The length of the LQOLP and similar instruments, and their specification of interview administration, represent serious constraints on their use for routine monitoring. Following the recommendations of Andrews et al. (1994), in relation to measures suitable for routine use, the Working Group wishes to encourage the development of two kinds of brief user-assessed quality of life measures. Firstly, the use of a generic health-related quality of life measure, such as the SF-36 and briefer measures like the five dimension EuroQoL as a core measure to be extended with mental health specific items, would have the benefit of facilitating comparisons between people with SMI and other populations. An SF-36 measure is currently being testing in the UK (Geertshuis et al. 1996), and it is recommended that similar research is undertaken to assess the suitability of the EuroQoL EQ-5D as a core measure. Secondly, the planned development of a self-assessment version of the Health of the Nation Outcome Scales (Wing et al. 1996) offers the promise of direct comparisons between clinical and user assessments. It has also been suggested that the value of such comparisons could be increased if the user version of HoNOS included an opportunity to rate the relative importance of the different problem domains in terms of their perceived impact on overall quality of life.

In summary, while further work is required to develop measures suitable for routine use, there are longer measures such as the LQOLP which are suitable for implementation on a sample survey basis where local circumstances and interests are supportive.
Further work required
Testing of the EuroQol EQ-5D among people with SMI.

Conclusion & priority
B. To be implemented where local circumstances allow by periodic survey.

References


Candidate indicator 10

Title Prevalence of side-effects associated with maintenance neuroleptics within a service provider population of people with SMI

Intervention aim Promote independent living and well-being.

Definition Two side-effects are monitored by the indicator:

- Tardive Dyskinesia: defined (within the relevant population) by Schooler and Kane (1982) criteria - i.e. movements rated ‘moderate’, in at least one, or ‘mild’ in at least two of the seven individual areas as assessed by the Abnormal Involuntary Movements Scale (AIMS; U.S. Department of Health Education & Welfare 1976).
- Tardive Akathisia: defined (within the relevant population) as a score of at least two on the Barnes Global Scale (Barnes 1989) - i.e. ‘mild akathisia’ implying: ‘awareness of restlessness in the legs and/or inner restlessness worse when required to stand still; fidgety movements present but characteristic restless movements of akathisia not necessarily observed; condition causes little or no distress’.

For a given mental health services provider, year and side-effect (defined above):

- **Numerator**: The number of people with SMI (in the care of the given provider) who have been maintained on prescribed neuroleptics for one year or more and who have been clinically assessed within the given year as suffering the given side-effect.

- **Denominator**: The number of people with SMI (in the care of the given provider) who have been maintained on prescribed neuroleptics for one year or more and who have been clinically assessed within the given year with respect to the given side-effect.

This fraction should be expressed as a percentage and reported with its numerator, both as an overall figure and by age group and sex.

Rationale The health outcome model for SMI specifies the promotion of ‘independent living and well-being’ as an aim of intervention among people with SMI. For a subset of this group, where maintenance neuroleptics are prescribed to reduce the risk of relapse, there is a risk that well-being may be compromised by the adverse side effects of the medication (e.g. involuntary movements, sexual dysfunction, sedation). Such adverse effects may also increase the risk of relapse by reducing compliance with neuroleptic therapy - although evidence in this area is limited (Kemp and David 1995).

The side-effect profiles of different antipsychotics vary, and are a major determinant of clinical choice in prescription (Barnes and Edwards 1993). At the population level, the success of attempts to minimise adverse reactions through the selection and modification of drug therapies will be reflected by indicators of the kind
specified here. From the range of known side-effects of neuroleptics, the selection monitored by this indicator, as currently defined, was limited by two factors. Firstly, effects should be associated with longer-term maintenance use, rather than being restricted to acute reactions to new therapy. Secondly, they should be open to objective observation, or subjective self-assessment, using established instruments suitable for making valid and reliable assessments in a service setting. The second of these criteria has proved to be a major constraint, with movement disorders being the single group of side-effects for which suitable measures are available from the literature (see further work required for discussion of additional measures of, particularly, subjective assessments of side-effects).

The indicator focuses on akathisia and dyskinesia as relatively prevalent and recognisable side-effects, and distinguishes tardive from acute forms on the basis of the medication history of the service-user. Parkinsonism is excluded as being a primarily acute reaction to anti-psychotics (Barnes and Edwards 1993). There is also no attempt to separately monitor tardive dystonia, due to the potential difficulty in isolating it from the dyskinesia with which it may co-exist (Barnes and Edwards 1993; Burke et al. 1982).

The indicator requires explicit reporting of the percentage of relevant service users for which a formal assessment of side-effects has been completed within the previous year. This requirement is intended to encourage formal assessments for all those on maintenance neuroleptics - defined here in relatively restrictive terms that require at least a full year on continuously prescribed anti-psychotic medication.

**Potential uses**
Clinical audit, provider based comparisons.

**Potential users**
Clinicians, commissioners.

**Possible confounders**
None identified.

**Data sources**
No current routine data sources capture the side-effect information required for this indicator. While case notes are likely to include records of observed side effects, they are unlikely to include the results of the formalised assessments required here. It is therefore suggested that data for this indicator are captured via periodic sample-based surveys of the relevant population.

**Data quality**
Inter-rater reliability will be critically dependent on adherence to the definitions and protocols of the specified measures.

**Comments**
None.

**Further work required**
The indicator as currently defined only monitors a subset of maintenance neuroleptic side-effects that might be judged by clinicians and/or users as having a significant potential impact on well-being. A range of cognitive and behavioural effects, together with weight gain and sexual dysfunction are obvious candidates.
for additional monitoring. However, in each of these areas, monitoring presents its own methodological problems that have yet to be addressed. Additional research on the overall pattern of side-effects in this population, and particularly their subjective impact on service users, is required to set monitoring priorities and act as a basis for developing routine measures.

**Conclusion & priority**  
A. To be implemented generally by periodic survey.

**References**


### Candidate indicator 11

**Title**  
Paid employment status of people with SMI

**Intervention aim**  
Promote independent living and well-being.

**Definition**  
Among a surveyed group of people with SMI: *the percentage of respondents falling into each of the following employment status groups (using Office of National Statistics definitions): ‘working full time’; ‘working part time’; ‘unemployed but seeking work’; ‘economically inactive’. The last should be further broken down into two ONS economic activity categories: ‘permanently unable to work due to long-term sickness or disability’ and ‘all other’. Median weekly hours should be reported for the ‘working part time’ group. The number of respondents and the response rate should also be reported. All figures should be broken down by age, sex and ethnic origin, as well as reported for the group as a whole.*

**Rationale**  
Work is widely recognised as a central component of the rehabilitation of people with SMI (Audit Commission 1994; Department of Health and Social Services Inspectorate 1994; Shepherd et al. 1994). While paid employment is only one of a range of potentially beneficial work-oriented activities, it is likely to have particular benefits - both financially and in terms its social status as an indicator of ‘normality’ (Shepherd et al. 1994). The indicator specified here presents the extent of paid employment among people with SMI, using an additional analysis to quantify the extent to which self-reported long-term disability underlies unemployment in this group.

The specified indicator’s use of standard ONS definitions of employment status has the advantage that comparative data relevant to a variety of populations will be available from the General Household Survey (Foster et al. 1995), the Health Survey for England (Colhoun and Prescott-Clarke 1996) and the Labour Force Survey (Office of Population Census and Surveys 1992). The interpretability of the indicator, in terms of trends over time or geographical differences, will depend in part on the availability of relevant comparison data on populations not defined by SMI. The OPCS Surveys of Psychiatric Morbidity (Meltzer et al. 1995a) employ the same employment status categories in an analysis of economic activity among adults with psychiatric disorders. These population based figures, while unable to identify a strictly defined SMI population, provide further relevant comparators for locally collected data on the employment status of people with SMI.

**Potential uses**  
Geographical and time-trend comparisons.

**Potential users**  
National and regional policy makers, commissioners, providers.

**Possible confounders**  
In addition to the success or failure of any interventions aimed at providing paid work opportunities for people with SMI, this indicator will be influenced by all the socio-economic and demographic factors affecting employment in general.
Data sources

Using the sources discussed in Indicator 1, a locally identified sample of people with SMI could be surveyed using the ONS standard questions and definitions. Within this sample, opportunistic data collection by the provider (e.g. as part of a care plan review) is unlikely to be satisfactory, as the possible association of review meetings with times of crisis for the service user could result in significant bias. Given this situation, it is likely that data collection will require additional contact with the user and the latter's consent to be included in a formal survey. It is probable that face-to-face contact will be required, as the alternatives of phone or postal surveys would run substantial risks of low and/or biased response rates. As this kind of survey procedure will be costly, data collection is most likely to be achieved through occasional regional or national surveys which give due consideration to the sample size required to examine time trends or geographical differences.

Data quality

The response rate will be dependent on the willingness of people who may be in considerable mental distress to take part in a survey of this kind. The response rate and the validity of the data collected may also be influenced by respondents' fears that full disclosure of their paid employment might jeopardise their continuing receipt of state benefits.

Comments

The proposed indicator addresses access to only one of the range of ordinary daytime activities that are likely to be important in the rehabilitation of people with SMI. Access to more broadly defined occupations is touched on by the Lancashire Quality of Life Profile (LQOLP; Oliver et al. 1996) and HoNOS (Wing et al. 1996) assessments, discussed in relation to Indicators 3 and 9 respectively.

Among questions on work, education and leisure activities, the LQOLP questions an interviewee's satisfaction with their 'job', and explicitly includes sheltered employment, occupational or industrial therapy, and 'studies' as occupations to be considered. Additionally, the interview asks:

- In the past year have there been times when you would have liked to have had more leisure activity but were unable?
- How satisfied are you with the amount of pleasure you get from things you do outside your home?

The HoNOS assessment also includes items relevant to individuals' daytime occupations. Scale 12 of the assessment, 'Problems with occupation and activities', (reproduced in Appendix D) requires the assessor to rate the problems faced by the individual in relation to the quality of the day-time environment, considering ‘...opportunities for maintaining or improving occupational and recreational skills and activities.' The assessor is instructed to consider factors such as access to supportive facilities rather than any aspect of functional disability.
In general the value of information regarding paid employment among people with SMI will be enhanced if linked data, such as that provided by the other assessments discussed here, are available on more broadly defined day-time occupation.

**Further work required**

None recommended.

**Conclusion & priority**

B. To be implemented where local circumstances allow by periodic survey.

**References**


Candidate indicator 12

Title Financial status of people with SMI

Intervention aim Promote independent living and well-being.

Definition Among a surveyed group of people with SMI: *the percentage of respondents falling into each of a set of weekly personal gross income bands (using the Office of National Statistics’ standard of: less than £20; £20-£39; £40-£59 etc.).* The number of respondents and the response rate should also be reported. All figures should be broken down by age, sex and ethnic origin, as well as reported for the group as a whole.

Rationale Money brings with it access to improved living conditions and increased choice as to how one’s time is spent. As a result the financial status of people with SMI may have a causal role in their capacity to cope with and/or minimise their disabilities. A shortage of money to cover expenses associated with transportation, entertainment and other goods and services tend to be ranked highly by people with severe mental illness among the daily problems that they face (Segal and Vandervoort 1993).

The indicator specified here uses standard income bands, intended to include all sources of income (earned, benefits, pensions and other), in order that income among people with SMI may be compared with general population data from, for example, the OPCS Omnibus Survey. The data may also be presented usefully in terms of median income, or as the percentage falling below a pre-determined poverty line.

Potential uses Geographical and time-trend comparisons.

Potential users National and regional policy makers, commissioners, providers.

Possible confounders This indicator will be influenced by all the socio-economic and demographic factors affecting income in general.

Data sources Using the sources discussed in Indicator 1, a locally identified sample of people with SMI could be surveyed using the relevant ONS standard questions and definitions. Alternatively, where the Lancashire Quality of Life Profile (LQOLP; Oliver et al. 1996) is employed to capture data for Indicator 3, income data will be available from the finances section of the instrument (see comments, below).

Within this sample, opportunistic data collection by the provider (e.g. as part of a care plan review) is unlikely to be satisfactory, as the possible association of review meetings with times of crisis for the service user could result in significant bias. Given this situation, it is likely that data collection will require additional contact with the user and the latter’s consent to be included in a formal survey. It is probable that face-to-face contact will be required, as the alternatives of phone or postal surveys would run substantial risks of low and/or biased response rates.
this kind of survey procedure will be costly, data collection is most likely to be achieved through occasional regional or national surveys which give due consideration to sample size.

**Data quality**

The response rate will be dependent on the willingness of people who may be in considerable mental distress to take part in a survey of this kind. The response rate and the validity of the data collected may also be influenced by respondents' fears that full disclosure of their income might jeopardise their continuing receipt of state benefits.

**Comments**

As noted above, the Lancashire Quality of Life Profile interview captures data on gross weekly income. Beyond this basic item, the finance section of the LQOLP collects a selection of further items regarding the financial status of the interviewee:

- *Which, if any, state benefits do you receive?*
- *In the past year have you been turned down for any state benefits for which you have applied?*
- *About how much more money per week do you need to be able to live as you would wish?*
- *During the past year have you ever lacked the money to enjoy everyday life?*
- *How satisfied are you with:*
  - How well-off you are financially?
  - The amount of money you have to spend on enjoyment?

Where possible, the interpretation of raw information on gross weekly income is likely to benefit from the availability of additional data on financial circumstances, such as those captured by the LQOLP.

**Further work required**

None recommended.

**Conclusion & priority**

B. To be implemented where local circumstances allow by periodic survey.

**References**


Candidate indicator 13

**Title**
Accommodation status of people with SMI

**Intervention aim**
Promote independent living and well-being.

**Definition**
Among a surveyed group of people with SMI: the percentage of respondents falling into each of a set of accommodation categories (to be determined). The number of respondents and the response rate should also be reported. All figures should be broken down by age, sex and ethnic origin, as well as reported for the group as a whole.

The Lancashire Quality of Life Profile (LQOLP; Oliver et al. 1996), discussed in relation to Indicator 9, includes a simple categorisation of accommodation:

- Hostel
- Private house (owner occupied)
- Boarding-out
- Private house (rental)
- Group home
- Flat
- Hospital ward
- Other
- Sheltered housing
- None.

However, a classification of this kind may in practice fall short of that required for the indicator. For example, it is important that homeless people within the survey group be identified reliably and validly. It is unclear how this group of respondents would be distributed across the ‘none’, ‘hostel’ and ‘other’ categories above. There may also be insufficient specificity in this list regarding residential care settings - greater detail has been obtained in a research context using relatively simple classifications of NHS and independent provision (Lelliott et al. 1966).

**Rationale**
The availability of stable and appropriate accommodation is likely to be an important factor in the rehabilitation of people with SMI. There is evidence that poor quality housing can directly affect the functioning of the severely mentally ill within the community (Baker and Douglas 1990). Disabling mental illness is particularly prevalent among the homeless (Gill et al. 1996) and there is evidence that the process of rehousing them in suitable accommodation (defined as ‘...small group homes or cluster flats supported by local social or psychiatric services’) is subject to great difficulties (Marshall and Gath 1992). Those who have conducted surveys of service users have also detected a desire for particular kinds of supported accommodation (e.g. small group homes rather than large staffed hostels; Shepherd et al. 1994) and the categorisation of accommodation used for this indicator should attempt to capture attributes of residential care relevant to such preferences.

**Potential uses**
Geographical and time-trend comparisons.

**Potential users**
National and regional policy makers, commissioners, providers.

**Possible confounders**
None identified.
Data sources

A survey of a locally identified sample of people with SMI. It is likely that a simple classification of accommodation type could be achieved from patient records.

Data quality

The basic facts of a service user’s place of residence are likely to be reasonably well recorded. The reliability with which that residence is classified is likely to be primarily dependent on the clarity with which the various accommodation categories are defined.

Comments

Beyond a basic categorisation of accommodation type, both the Lancashire Quality of Life Profile (Oliver et al. 1996) and HoNOS (Wing et al. 1996) assessments, discussed in relation to Indicators 3 and 9 respectively, include items relating to a qualitative assessment of living conditions.

Having categorised the interviewee’s place of residence according to the categories listed in the definition section above, the LQOLP asks a number of follow-up questions:

- How long have you lived here?
- How many people live here too?
- Do your family live here too?
- In the past year have there been times when you wanted to move or improve your living conditions but were unable to do so?
- How satisfied are you with:
  - the living arrangements here?
  - the amount of independence you have here?
  - living with the people who you do?
  - the amount of privacy that you have here?
  - the prospect of living here for a long time?

The HoNOS instrument includes an assessment of the ‘problems with living conditions’ faced by an individual. This considers whether basic necessities are met, and beyond this whether there is help to cope with disabilities and opportunities for development.

Where possible, the interpretation of raw information on the type of accommodation available to people with SMI is likely to benefit from the availability of additional data on the quality and perceived appropriateness of that accommodation, such as those captured by the instruments discussed here.

Further work required

None recommended.

Conclusion & priority

B. To be implemented where local circumstances allow by periodic survey.
References


Candidate indicator 14

Title
Summary of a measure of user satisfaction with respect to a specific mental health service, among people with SMI

Intervention aim
Sustain a collaborative approach between service providers and service users and their carers.

Definition
For the population of people with SMI making use of a given mental health service in a given survey period: a summary of users’ responses to a standard service-specific questionnaire assessing their satisfaction with the health care provided by that service. Summary statistics describing the distributions of responses for each of the topics addressed by the questionnaire should be reported by user age-group, ethnic origin and sex.

Topics to be covered by the questionnaire should be selected in consultation with a representative sample of service users, and should include aspects of the treatment provided, as well as more peripheral issues relating to e.g. the hotel services associated with in-patient care.

Rationale
‘Patient satisfaction’ has been properly criticised when advanced as a catch-all method for assessing mental health care from the user’s perspective (Williams and Wilkinson 1995). However, both user representatives (e.g. Rogers et al. 1993) and health care professionals (e.g. Caan 1993) have found value in identifying aspects of care associated with substantial dissatisfaction.

The proposed indicator has a similar purpose, and aims to identify problem areas in a particular service by providing a basis for comparisons between the levels of satisfaction expressed by users of similar mental health services in different places. This aim leads to the indicator’s requirement for a standard questionnaire for a given type of service (e.g. acute in-patient, day centre, drop-in service). A structured questionnaire is specified as the basis for the assessment (as opposed to a semi-structured interview or other more qualitative approaches such as those based on focus groups) to enhance the reliability of the indicator with respect to inter-service comparisons, as well as to make use of the indicator as practical as possible in a wide range of settings. The paper questionnaire method also has advantages in terms of confidentiality for respondents who are likely to have continuing contact with the service on which they are invited to comment. However, it is recognised that the reduction of a complex set of perceptions to a series of rating scales will result in the loss of potentially valuable information (Williams 1994). It is therefore emphasised that the quantitative nature of the indicator, while aiming to highlight differences between services, should not be mistaken for detail or depth.

Potential uses
Provider-based comparisons; time trend analyses by individual providers.
Potential users

Providers, commissioners, service users.

Possible confounders

Provider based comparisons of service quality, as reflected in user satisfaction, are open to confounding with a wide range of case-mix factors (Fitzpatrick 1990). The specified reporting by age and sex will provide a degree of control, but some measure of the extent of users’ experience of the particular service, or mental health services in general, may well also be useful (Calnan 1988). An examination of satisfaction data and user characteristics, collected to a common standard across providers, will be a useful source of information on the important case-mix determinants of user satisfaction.

It should be borne in mind that any provider-based satisfaction survey will be unresponsive to those so dissatisfied with the service offered that they no longer make use of it.

Data sources

A wide range of instruments under the broad heading of ‘patient satisfaction’ have been developed for use in the mental health care field (Lebow 1983; Bowling 1995). However, many are directed at aspects of life outside the provision of health care (e.g. satisfaction with housing or social networks), or concentrate exclusively on the hotel services or physical surroundings associated with a service – at the expense of issues more central to the therapeutic process. Furthermore few instruments are backed by extensive testing of their psychometric properties – one of the factors leading Andrews et al. (1994) not to recommend any of the eight measures they reviewed.

The Client Satisfaction Questionnaire (Larsen et al. 1979), further developed in the UK as the General Satisfaction Questionnaire by Huxley and Warner (1992), does offer a model of one kind of instrument that would serve this indicator. In its earlier incarnation it was backed by encouraging validity and reliability data and it has an appropriate focus on the health care needs of the respondent. However, although its fairly non-specific wording may offer relevance to a range of services, this general purpose nature is likely to have disadvantages relative to a set of service-specific instruments.

In view of the lack of an obvious preferred instrument in the literature, it is proposed that additional development work, drawing on recent UK experience of user satisfaction audits such as the Maudsley questionnaire (Caan 1993), is undertaken to produce and pilot-test a set of service specific instruments to support this indicator. As noted in the indicator specification, the identification of topic areas should be informed by consultation with service users. To facilitate comparisons between different types of service, it may be appropriate to develop a set of core questions suitable for a variety of settings, and combine them with additional service specific items.
Data quality

The response rate obtained for an anonymous paper questionnaire is likely to be the limiting factor on data quality. Low response rates (around 50%) may in part explain substantial differences between different surveys asking similar questions (Crowe et al. 1994). In order to estimate the degree to which responders are representative of the population, an anonymous survey will have to include an opportunity for self-report of relevant demographic and service-use variables.

The exclusion from user satisfaction surveys of people with visual or cognitive disabilities, or who are not English speaking, may have a systematic effect on aggregate satisfaction data.

Comments

None.

Further work required

Development and pilot testing of service-specific user satisfaction questionnaires.

Conclusion & priority

Initially: D. To be further developed because indicator specification is incomplete.
In the longer term: A. To be implemented generally by periodic survey.

References


Candidate indicator 15

Title
Percentage of CPA care plans for people with SMI signed by their users

Intervention aim
Sustain a collaborative approach between service providers and service users and their carers.

Definition
For a given mental health services provider and year: the number of care plans (including reviews of pre-existing care plans) for people with SMI assigned a key worker within the given provider, which are dated within the given year and signed by the service user to indicate understanding and acceptance, divided by the number of care plans/reviews (for people with SMI assigned a key worker within the given provider) which are dated within the given year. The resulting fraction should be reported as a percentage, together with its numerator. In addition to being reported for all cases, the statistics should be broken down by primary diagnosis (at the level of ICD-10 two-character code) and, within diagnosis, by age ethnic group and sex.

Rationale
The involvement of service users in the development and review of care plans is considered an important aspect of the Care Programme Approach (Department of Health 1990; Department of Health 1995). The user's signature – in a context indicating their understanding and acceptance of a plan – is taken as evidence of the intended collaborative approach. The NHSE's Audit Pack for Monitoring the CPA, developed by the Royal College of Psychiatrists' Research Unit (National Health Service Executive 1996) identifies the percentage of care plans signed by users (on the higher tiers of CPA) as an indicator of the quality of the CPA process, and suggests that it is monitored at the provider level.

Potential uses
Local provider-based audit; comparisons between providers and over time.

Potential users
Providers, commissioners, service users.

Possible confounders
None identified.

Data sources
Local arrangements for audit of CPA records, perhaps on a sample basis, are likely to be the most practical method for implementing this indicator. The NHSE Audit Pack provides a suitable monitoring tool for all care plans associated with the higher tiers of CPA. Additional data collection from CPA records would be required to identify the subset of service users falling within the operational definition of SMI.

Data quality
The validity of the indicator as a measure of even basic collaboration between user and provider will require clear documentation of the care planning/review process.

Comments
None.
Further work required

The meaning of a user's signature on a care plan will depend on the context in which it is obtained. Relatively high signing rates could probably be obtained by presenting the need for a signature as a simple administrative chore. To make this indicator more meaningful, there is a need for a group of users and clinicians to work together on a standard statement for inclusion in care plans, the signing of which by a user would imply acceptance and understanding of the care plan. Critically, any such statement should make it clear that there is no obligation for the user to sign. The results of this process, together with experience from the national audit of the CPA must be obtained before this indicator can be fully evaluated.

Conclusion & priority

D. To be further developed because link with effectiveness is not clear.

References


Title Assessment of impact of SMI on carers

Intervention aim Support carers and reduce impact of SMI on them.

Definition Two alternative approaches to the assessment of the impact of SMI on carers are considered.

One approach is to undertake an assessment across the various causative factors thought to underlie the impact on carers (see Appendix H). The seven dimensions identified are:

- information and skills
- depression, anxiety and stress
- satisfaction with care and with caring
- social support and networks
- services
- financial outcome
- physical health status.

A second method is to undertake a more direct assessment of the effects of caring by using a questionnaire based measure. A number of such measures exist, such as the Care-Giver Strain Index (Robinson 1983) and the Relatives' Stress Score (Greene et al. 1982). Other simpler tools exist which assess the intensity of caring required, such as the critical interval method of assessing need, where the carer indicates the length of time a person can be left without needing attention (Issacs and Neville 1976).

Whichever method or approach is used, it will be necessary to define the carer population. Some definitions of carers are available from the literature, for example, a ‘carer’ may be defined as:

- Anyone who looks after or cares for a handicapped person to any extent in their own home or elsewhere (Equal Opportunities Commission 1982).
- A person looking after or providing some form of regular service for a sick, handicapped or elderly person living in their own or another household (Green 1988).

Within the context of mental health, it has been suggested that carers could be defined as ‘concerned relatives or friends who have the person’s interests at heart’ (Oxfordshire Mental Health Campaign Group 1997). However, any of the above definitions may prove difficult to operationalise. Local authority definitions of carers, while variable and therefore unable to support comparisons between populations, may provide a practical alternative for identifying relevant individuals.

Rationale The impact of SMI on carers is multi-dimensional incorporating issues of support, help, protection, and social dynamics as well as the physical and behavioural
aspects (Quereshi 1986; Pearlin et al. 1990). In a survey of views regarding the key elements of a care package for people with schizophrenia in the community (Shepherd et al. 1994) family carers concluded that the areas: professional support; treatments; physical health; finance; social contacts; and supports were of the greatest importance. They also wanted more information about the illness, and advice about management, as well as acknowledgement by professionals of their status as main carers. Another similar study looking at the views of carers of people with manic depression supported these findings (Hill et al. 1996). More specifically, the Oxfordshire Mental Health Campaign Group summarised the following expectations of carers as:

- a reliable service
- respect
- offers of help
- offers of advice
- help in a crisis and when requested
- information
- their needs to be taken into account
- respite from caring if they need it
- practical help in their caring role like other carers
- to maintain a reasonable lifestyle
- to be consulted about the services provided in ways that suit them.

More recently the effects of caring on the carers themselves have to some extent been acknowledged with the introduction of the Carers Act. Assessments of the impact on carers may provide useful information to identify the needs of the carer and the person being cared for, and assess the adequacy of existing services or the effect of specific interventions which aim to alleviate the problems of carers.

**Potential uses**
Local clinical audit, assessment of local trends over time.

**Potential users**
Providers, clinicians, commissioners, public.

**Possible confounders**
Carers’ perception of the effects of their role may be related to their own physical, social and mental state as well as other factors. A more general assessment using a multi-dimensional instrument such as the General Health Questionnaire (Goldberg 1972) may be appropriate, used in conjunction with a more specific assessment of the stresses experienced by carers (Philp 1994).

**Data sources**
Currently, little information is documented about carers on a routine basis. New data sources and instruments would be required to collect relevant data. Direct communication with the carer may be the most reliable source, despite the inherent bias and interpretation issues. If the carer were to be the source of the information, a self-administered questionnaire may be suitable.
While some of the practical difficulties of data collection can be addressed, it must be recognised that the effects of caring constitute a particularly sensitive issue. Individuals receiving questionnaires may not identify themselves as a carer or may feel uncomfortable about the care of a loved one being addressed in negative terms of ‘burden’ or ‘strain’. Equally some carers may not be in sympathy with the person for whom they are caring, as they are often forced into the role. Additionally, routine measurement of the impact of caring may raise expectations of additional assistance under circumstances that may not be met.

**Data quality**

The quality of the data would depend on the source. Any questionnaires designed and developed to be completed by the carer would need field testing for validity and reliability. Alternative systems for capturing this information either within a hospital or general practice would also need evaluation to determine the nature of the data and the likely availability.

Both the Care-Giver Strain Index and Relatives’ Stress Score have been used in several research studies and are brief, and found to be practical. The former was developed to detect ‘strain’ among carers of physically-impaired elderly people living at home in the United States. Encouraging results with respect to validity and reliability have been obtained in this population. The Relatives’ Stress Score was developed to assess the amount of stress and upset experienced by relatives as a result of caring for an elderly mentally impaired person living at home. Both scales, although requiring further testing in SMI populations with different needs, have been judged to be potentially valuable instruments which could be incorporated into clinical practice (Philp 1994).

**Comments**

The interactions between people with severe mental illness and their informal carers is complex and based on mutual personal relationships which are different from the relationship between a service user and a formal care provider. Many people with severe mental illness live independently without a carer and some do not consent to receiving support from a self-appointed carer. There may be conflicts of interest between carers and service users, and it should be recognised that carers’ views cannot be assumed to tell us anything about the views of service users.

**Further work required**

Further research is required before any recommendations can be made regarding the capture of information about the effects of caring in relation to SMI. This may lead to the development of a mental health specific instrument. The importance of this issue makes this work of high priority.

**Conclusion & priority**

Initially: D. To be further developed because indicator specification is incomplete.

In the longer term: A. To be implemented generally by periodic survey.
References


**Candidate indicator 17**

**Title**  
Mortality among people with SMI

**Intervention aim**  
Ensure protection and good physical health of service users.

**Definition**  
For a given resident population, year and type of death (defined below): the number of people with SMI, registered as having died in the given year, divided by the number of people with SMI in the population. The resulting fraction should be reported with its associated numerator as an overall crude and age-standardised figure, and by age-group, ethnic origin and sex.

Four types of death are used as the basis for reporting:

- natural causes
- suicide
- homicide
- other non-natural causes.

Additionally, a combined all-causes mortality rate should be reported.

**Rationale**  
Life expectancy of people with severe mental illness is lower than the general population and they are at greater risk of dying from all causes (Prior et al. 1996). Calculation of these rates will allow regional and national comparisons with the general mortality rate and the monitoring of trends over time. People with SMI are at particular risk of suicide (Hawton 1987). A reduction in the suicide rate of people with SMI is a Health of the Nation Target (Department of Health and Social Services Inspectorate 1994) and a range of suicide prevention initiatives are in development or in place (Jenkins et al. 1994) and this indicator provides a measure of the effectiveness of such interventions.

**Potential uses**  
Population-based comparisons; assessment of regional/national trends or progress towards targets.

**Potential users**  
National/regional policy makers, commissioners, providers.

**Possible confounders**  
A wide variety of causes will underlie the mortality statistics defined here, and variations in this indicator may not be wholly attributable to changes in the support and services specifically available to people with SMI. Additionally, variations in the provision and uptake of specialist mental health services may influence the number of people identified as having SMI.

**Data sources**  
In general this indicator may be derived from the linkage of death certificate data with records identifying individuals with SMI. Linking such records is likely to become easier to accomplish following full implementation of the NHS number. The specification for Indicator 1 discusses data sources for the identification of people with SMI and, ideally, the indicator defined here would draw on a population based register of people meeting the operational definition of the
condition. However, in the absence of such a specific register, it may be practical to first link death certificate data with a more inclusive database (e.g. a register covering all service users within the Care Programme Approach) and subsequently identify, from clinical records, the subset of linked records associated with people meeting the operational criteria for SMI.

In the case of records relating to suicides health authorities are already required to report the common information core (National Health Service Executive 1995) statistic C4 ‘Rate of suicides of people with a mental illness subject to the Care Programme Approach’. It may be that the local data collection schemes put in place to meet this requirement could be adapted to support the SMI specific indicator defined here. Furthermore, the ongoing Confidential Inquiry into Homicides and Suicides by Mentally Ill People (Steering Committee of the Confidential Inquiry 1996) will continue to administer a national system for identifying potentially relevant cases of suicide. Any attempts to develop local data collection systems in support of the indicator specified here should investigate the availability of data collected for submission to the Inquiry.

**Data quality**

The accuracy of this indicator will be primarily dependent on the completeness of computerised registers based on individuals’ use of specialist services. This aspect of data quality should be monitored as such registers are established to support the Care Programme Approach and developments such as the new mental health minimum data set.

The analysis of trends over time with respect to mortality data, where it is broken down across the four types of death, may be influenced by changes in certification practice. The potential for under-recording of suicides by coroners is to some extent addressed by an inclusive definition of suicide incorporating all deaths associated with a cause of ‘intentional self-harm’ (ICD-10 X60-X84) or ‘event of undetermined intent’ (ICD-10 Y10-Y34) (Wing 1994).

**Comments**

None.

**Further work required**

Continuing evaluation of current and proposed data sources.

**Conclusion & priority**

Initially: A. To be implemented generally by periodic survey.
In the longer term: C. To be implemented following development of information systems on a routine basis.
References


**Candidate indicator 18**

**Title**
Use of non-psychiatric health care services by people with SMI

**Intervention aim**
Ensure protection and good physical health of service users.

**Definition**
For a given resident population and time period: the number of attendances at (1) GP surgeries and (2) A&E departments for non-psychiatric illness by people with SMI, divided by the number of people with SMI. Fractions (1) and (2) should each be expressed as a percentage and reported with its associated numerator as an overall figure and by age-group, ethnic origin and sex.

**Rationale**
Psychiatric morbidity is associated with an increased prevalence of physical complaints and higher than normal rates of attendance at GPs’ surgeries for those complaints (Meltzer et al. 1995b). Additionally, the lower physical health status reported by people with a mental illness is accompanied by a reduced likelihood of having a regular family doctor and an increased use of A&E services (Clark 1995). More generally, there is evidence from UK (Brugha et al. 1989) and US (Roca et al. 1987) studies that there is significant unmet need with respect to physical complaints among the long-term mentally ill.

This indicator takes levels of service use (excluding attendances explicitly related to mental health problems) as a proxy for physical illness. It can be argued that a variety of positive factors, including improved living conditions, the alleviation of mental distress, and the avoidance of treatment side effects might all contribute to maintaining good physical health.

**Potential uses**
Population-based comparisons; assessment of trends or progress towards targets.

**Potential users**
Commissioners, clinicians, policy makers, provider management.

**Possible confounders**
Being a proxy for physical illness, based on service use, this indicator may be influenced by the access to care afforded people with SMI. A reduction in GP consultations for physical complaints by people with SMI might reflect increased practical obstacles to surgery attendance, or the perception that there was an undue likelihood that physical symptoms would be treated as manifestations of psychiatric disease. In this respect the indicator based on A&E attendances may have an advantage as it may be sensitive to physical disease that has not been detected and managed within the primary care setting.

**Data sources**
The widespread implementation of the accident & emergency minimum data set, and the proposed mental health minimum data set (MHMDS; see Appendix I), would allow the rate of A&E attendances among people with SMI to be calculated from linked records. Where diagnostically coded consultation records are available from GP information systems, these may also be linked with MHMDS records, in order to calculate the GP attendance rate for physical complaints.
In the absence of computerised data covering GP and A&E activity, the indicators might be calculated from a review of clinical notes from these settings, for a previously identified sample of people with SMI.

**Data quality**
The completeness and quality of novel minimum data sets will be open to question.

**Comments**
None.

**Further work required**
The potentially complex manner in which this indicator may confound physical illness with access to care requires further investigation before a firm recommendation regarding its utility can be made. This conclusion is underlined by the fact that, in advance of developments in information systems, the indicator would rely on a labour intensive review of case notes.

**Conclusion & priority**
D. To be further developed because link with effectiveness is not clear.

**References**


Candidate indicator 19

| Characteristics | Population | Cross-sectional | Direct |

**Title**
Number of homicides by people with SMI

**Intervention aim**
Ensure protection of carers, service providers and the public.

**Definition**
For the national population and a given year: *the number of homicides by people with SMI*. This figure should be reported alongside the total number of homicides occurring in the same period.

**Rationale**
Homicide by people with SMI reflects a failure to protect the population from the dangerous behaviour of people with SMI. Thirty-nine homicides by people under the care of, or recently discharged from, the specialist psychiatric services occurred during the two year period reviewed by the Confidential Inquiry into Homicides and Suicides (Steering Committee of the Confidential Inquiry 1996). In view of the small number of cases, and their importance as individual events, it was felt that presentation as an absolute number rather than a rate was appropriate. However, in order to give a sense of proportion between this number and the total number of homicides, the latter is to be reported also.

**Potential uses**
Assessment of national trends over time.

**Potential users**
National/regional policy makers, commissioners, clinicians, the public.

**Possible confounders**
None identified.

**Data sources**
Following its first full report, The Confidential Inquiry into Homicides and Suicides is to continue, and for the foreseeable future is likely to be the appropriate basis for collating the indicator specified here. The Inquiry has in the past brought together Home Office data on homicide cases associated with prior contact with the specialist mental health services, with questionnaire data gleaned from the relevant mental health team. In theory, both the initial analysis of the Home Office data and the content of the questionnaire could be adapted to identify those cases meeting the operational definition of SMI.

**Data quality**
The completeness of the Inquiry’s case ascertainment has been questioned (House 1996). However, this apparent criticism may also be seen as a suggestion that the Inquiry’s remit is broadened to include the 100 or so homicides per annum committed by those judged legally ‘abnormal’ (Steering Committee of the Confidential Inquiry 1996). For the indicator specified here, the completeness of case ascertainment - with respect to the operational definition of SMI - will require testing.

**Comments**
None.

**Further work required**
Liaison with the relaunched Inquiry to establish methods whereby the subset of homicides within its remit, which also meet the operational criteria for SMI, can be identified.
Severe Mental Illness Outcome Indicators

Conclusion & priority

A. To be implemented generally by periodic survey.

References


**Candidate indicator 20**

<table>
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<td><strong>Timeframe:</strong></td>
<td>Cross-sectional</td>
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<tr>
<td><strong>Outcome relationship:</strong></td>
<td>Direct</td>
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</table>

**Title**

Incidence of serious physical injury resulting from assaults on staff and service users by people with SMI

**Intervention aim**

Ensure protection of carers, service providers and the public.

**Definition**

For a given mental health service provider and year: the number of serious physical assaults (defined below) on (1) staff and (2) service users by people with SMI, occurring during the given year, divided by the number of people with SMI under the care of the provider during the given year. The resulting rates should be reported with their associated numerators both as overall figures and by age-group, ethnic origin and sex.

Following the definition of a third-degree assault used by the Monitoring Inner London Mental Illness Services Group (MILMIS Project Group 1995), a serious physical assault is defined as: an assault resulting in major physical injuries including large lacerations, fracture, loss of consciousness, or any assault requiring subsequent medical investigation or treatment.

**Rationale**

Serious physical attacks on staff by people with SMI do occur and are often difficult to predict (Walker and Siefert 1994). It is important that staff and users are protected from attack as much as possible. This indicator will identify providers which appear to have a relatively high level of attacks and thus focus further investigation. A provider’s physical accommodation, staff development and appropriateness of treatment may all influence the rate of attacks.

**Potential uses**

Provider based comparisons; assessment of regional and national trends over time.

**Potential users**

Provider management, clinicians, commissioners.

**Possible confounders**

The denominator is simply defined as the total number of people with SMI within the provider’s caseload for the year. For valid comparisons to be made between providers with substantially different annual throughputs of cases, it may be appropriate to additionally analyse assaults in terms of (for example) the number per service-user month.

**Data sources**

An estimate of a provider’s caseload with respect to people with SMI would rely on the sources discussed in Indicator 1. Routine records are made of attacks by service users, in line with Health and Safety regulations. A review of these records could identify those cases associated with people meeting the operational criteria for SMI.

**Data quality**

There is evidence that assaults tend to be under-reported by the routine monitoring procedures (Walker and Siefert 1994).
Comments

While the indicator specified here covers physical assaults on staff and service users, informal carers constitute a third ‘at risk’ group. Although the collection of data on assaults on carers is likely to be problematic, the occurrence of such assaults is a particularly important issue and research should be undertaken to identify methods by which it can be surveyed and reported upon in an additional indicator.

Further work required

Development of an indicator of the occurrence of assaults on carers.

Conclusion & priority

B. To be implemented where local circumstances allow by periodic survey.

References


5. RECOMMENDATIONS

To be implemented generally by periodic survey

5.1 It is recommended that the following indicators initially be implemented generally by periodic survey (the numbers for the indicators refer to those used in Section 4):

1: prevalence of severe mental illness
10: prevalence of side effects associated with maintenance neuroleptics within a service provider population of people with severe mental illness
17: mortality among people with severe mental illness
19: number of homicides by people with severe mental illness.

In the longer term, indicators 1 and 17 could be implemented routinely after IT development.

5.2 The prevalence of severe mental illness at the present time can only be obtained by periodic survey. The operational definition of the condition requires a diagnosis, HoNOS score and/or defined length of contact with mental health services. The value of the indicator will be enhanced by reporting the prevalence for the sub-groups of people at greatest risk such as those in prisons or who are homeless. With the introduction and computerisation of the new Mental Health Minimum Data Set it should be possible to collect prevalence data routinely.

5.3 Maintenance neuroleptics have adverse effects such as involuntary movements and sedation which compromise well-being and may lead to medication not being taken and thus relapse. The indicator monitors two side effects, tardive dyskinesia and akathisia which have been judged to have a significant impact on well-being. As case-notes are unlikely to include the results of comprehensive assessments routinely, these data are best collected by periodic surveys of the relevant population.

5.4 The mortality indicator identifies separately deaths from natural causes, suicide, homicide, and other non-natural causes. People with severe mental illness are at greater risk of suicide than the general population. Unlike the target developed for the Health of the Nation monitoring, this indicator relates only to suicides in people with severe mental illness. The life expectancy of people with severe mental illness is lower than the general population and they are at greater risk of dying from all causes. This indicator requires the linking of death certification data with records which identify individuals who have severe mental illness. The linking of these data will be possible with the full implementation of the NHS number and the setting up of a population based register of people meeting the operational definition of severe mental illness.
5.5 **Homicide** by people with severe mental illness reflects a failure to protect the population from the dangerous behaviour of a very small number of people. About 20 homicides per year are carried out by people under the care of, or recently discharged from, specialist psychiatric services. These data should be collected by periodic survey and, in view of the very small numbers, expressed as an absolute number nationally rather than a rate.

To be implemented where local circumstances allow by periodic survey

5.6 It is **recommended** that the following indicators be implemented initially where local circumstances allow by periodic survey:

3: HoNOS scores for a service provider population of people with severe mental illness
4: proportion of people with severe mental illness lost to follow-up by specialist services
5: proportion of people with severe mental illness discharged from follow-up by specialist services
9: user-assessed health-related quality of life for a service-provider population of people with severe mental illness
11: paid employment status of people with severe mental illness
12: financial status of people with severe mental illness
13: accommodation status of people with severe mental illness
20: incidence of serious physical injury resulting from assaults on staff and service users by people with severe mental illness.

In the longer term, indicators 3, 4 and 5 could be implemented routinely after IT development.

5.7 **HoNOS scores** are designed to record a concise clinical assessment of the severity of a range of health and social problems likely to be experienced by people with severe mental illness. The indicator recommended provides a cross-sectional view of a service user population and, as such, is likely to be useful in comparing providers serving similar populations. With more experience of interpreting information based on HoNOS, it may be possible to develop longitudinal indicators in which a current score is compared with a previous ‘best’ or personal norm.

5.8 **Follow-up arrangements** are a crucial part of the Care Programme Approach. When each contact with a service user is entered on computer it will be possible to derive this indicator routinely. For the present, it may be appropriate to restrict it to a survey of the people with severe mental illness who are on a supervision register.
5.9 **Discharge from specialist care** has been taken to be a proxy for recovery. This activity-based measure will be calculated readily following the implementation of a computerised Mental Health Minimum Data Set. Until then, these data will have to be collected by a periodic survey of case records.

5.10 Tools are now available to allow service users to assess their **health-related quality of life**. Two measures seem to be preferred, namely the Lancashire Quality of Life Profile (LQOLP) and the Quality of Life Schedule (QLS). Both these approaches may be too time-consuming for a routine setting and further work is needed to develop and test shorter instruments such as the EuroQol EQ-5D.

5.11 **Paid employment** is widely recognised as a central component of the rehabilitation of people with severe mental illness. This indicator presents the frequency of paid employment with an additional breakdown to quantify the extent to which self-reported long-term disability underlies unemployment. It addresses access to only one of the range of ordinary day-time activities of relevance to people with severe mental illness. The broad based instruments, LQOLP and HoNOS, have questions related to employment.

5.12 The **financial status** of people with severe mental illness may have a causal role in their capacity to cope. The indicator is derived from standard Office of National Statistics data items. Data about finance is also included in the LQOLP.

5.13 The availability of stable and appropriate **accommodation** is an important factor in supporting people with mental illness. Sophisticated information about housing is available in LQOPL and QLS, and the HoNOS include an assessment of any problems with living conditions. Indicator 13 is obtained from a sample survey using the simple classification of accommodation type included as part of LQOPL.

5.14 The indicator about **serious physical injury resulting from assaults** will help to identify providers which need to review their procedures for reducing harm to staff and other service users. Data to derive this indicator should be available from routine records kept to comply with Health and Safety regulations.

**To be implemented following IT development on a routine basis**

5.15 It is **recommended** that the following indicators be implemented following IT development on a routine basis:

6: proportion of people with severe mental illness spending more than 90 days in a given year in in-patient psychiatric care
7: longitudinal indicators of change in item, subscale and total HoNOS scores among people with severe mental illness admitted to in-patient psychiatric care
8: hospital re-admission frequencies for a resident population of people with severe mental illness.

5.16 A high proportion of people with severe mental illness spending more than 90 days in a given year in in-patient psychiatric care may suggest that local care in the community is ineffective. The data to derive the indicator will be available with the universal implementation of the new Mental Health Minimum Data Set and the NHS Number.

5.17 HoNOS scores on admission and at discharge and/or 90 days after discharge will provide information about whether the admission helped to restore function or prevent relapse. Once HoNOS scores and their components are computerised routinely it will be possible to derive these longitudinal indicators from HoNOS data.

5.18 An unusually high rate of frequent admissions may indicate a high level of relapse and may be a useful indication of the effectiveness of post-discharge support. Interpretation of this indicator will need to take into account a number of factors and it will not be possible to derive it until the new Mental Health Minimum Data Set and the NHS number have been implemented universally.

To be further developed

5.19 It is recommended that the following indicators require further work initially in developing the method of measurement or in identifying their link with effectiveness:

2: in-patient admission on detection of severe mental illness mental health service, among people with severe mental illness
14: summary of a measure of user satisfaction with respect to a specific mental health service, among people with severe mental illness
15: percentage of CPA care plans for people with severe mental illness signed by the users
16: assessment of impact of severe mental illness on carers
18: use of non-psychiatric health care services by people with severe mental illness.

In the longer term, indicators 14 and 16 could be implemented generally by periodic survey.
5.20 The rationale behind Indicator 2 was that if the first contact with mental health services was an in-patient admission, it might suggest a failure to detect the early signs of mental illness. The implementation of the Mental Health Minimum Data Set will allow the identification of a first-ever mental health service contact but further work needs to be done to identify the utility of this indicator and its relationship with effectiveness.

5.21 The aim of Indicator 14 was to identify problems in a service by providing a basis for comparisons between the levels of satisfaction expressed by service users in different places. No obvious preferred measurement instrument has been identified and further development work is required to produce and validate a set of data which will support this indicator.

5.22 The involvement of service users in the development and review of care plans is considered an important aspect of the Care Programme Approach. However, the significance of a user’s signature will depend on the context in which it is obtained. To make this indicator meaningful it is essential that users and clinicians agree a standard statement for inclusion in care plans about the implications of signing them.

5.23 The impact of severe mental illness on carers is multi-dimensional incorporating issues of support, help, protection and social dynamics as well as the physical and behavioural aspects. Currently, little information is recorded about carers and no measurement tool for routine use has yet been developed. The Group considers that the development of a routine specific instrument for measuring the impact of the condition on carers is a high priority for research.

5.24 Psychiatric morbidity is associated with an increased prevalence of physical illness and a higher than normal use of non-psychiatric health care services. The compilation of the indicator will require the linking through the NHS number of general practice, accident and emergency, and out-patient computerised data. Work also needs to be done on how to interpret the information and whether it is related to the effectiveness of service provision.

Conclusions

5.25 Our work on outcome indicators for severe mental illness has highlighted the need for urgent progress in the development and implementation of data sets and systems, in particular:

- a universally acceptable definition of severe mental illness
- minimum data set for mental illness
- Health of the Nation Outcome Scales
- mechanisms for data linking.
5.26 The operational definition of severe mental illness recommended in our report reflects the service providers’ perspective only. The Group recommends that as a matter of urgency the Department of Health commission further work to:

- encompass the service users’ perspective, particularly those from ethnic groups
- test operational definitions with a wide range of service users and providers.

5.27 The current proposals for the new minimum data set are summarised in Appendix I. As foreseen by the NHS/DHSS Health Services Information Steering Group (1982) recommendations about data sets have a finite life and must be updated as clinical and managerial processes change. The Korner Steering Group’s data sets became time-expired in the late 1980’s and the implementation of a new data set for mental health is long overdue.

5.28 The Health of the Nation Outcome Scales, reproduced in Appendix D, are a major advance in the recording of psychiatric morbidity. It is essential that they are implemented universally and further developed in the light of the experience of their use in clinical and managerial situations.

5.29 Crucial to the development of mental health information is the ability to link data from difference sources. Indicator 17, concerning mortality among people with severe mental illness, for example requires the linkage of death certificates with records identifying individuals with severe mental illness. Ideally, this is best achieved with a population based register of people meeting the operational definition of the condition. However, in the absence of a specific register, it may be possible with the full implementation of the NHS number and a Care Programme Approach to link the requisite data to produce this indicator.
APPENDIX A: BACKGROUND TO THE WORK

Summary

A1. Over the last few years a major component of the Department of Health's and NHS Executive's strategy has been to promote the development and use of measures of health outcome. In July 1993 the Central Health Outcome Unit (CHOU) was set up within the Department of Health (DoH). Commissioned by the DoH, in 1993 a feasibility study of potential outcome indicators was published by the Faculty of Public Health Medicine and a package of indicators was published by the University of Surrey for consultation. Following these two phases of development, a third phase of work was initiated by the CHOU. Its remit is to report on ‘ideal’ health outcome indicators.

Central Health Outcome Unit

A2. The CHOU is an internal DoH unit whose goal is ‘to help secure continuing improvement in the health of the people of England through cost-effective and efficient use of resources’ (Lakhani 1994). The objectives of the Unit are to:

- encourage and co-ordinate the development of health outcome assessment, particularly in respect of the development of appropriate methods, appropriate data collection systems, expertise, analytical skills, and interpretation
- encourage and support the use of health outcome assessment and information in making policy about health interventions and in the planning, delivery and monitoring of services.

A3. Several national committees have a special interest in outcomes and are kept informed of progress:

- Clinical Outcomes Group
- Public Health Network
- CMO’s Working Group on Information Management and Technology.

Phases 1 and 2

A4. The Faculty of Public Health Medicine was commissioned to undertake a feasibility study of potential indicators which reflect health end-points for health services and which cover topics in which health care has an important contribution to make. This work, (McColl and Gulliford 1993), was constrained in that the set of indicators were to:

- be based on reliable routinely collected data
- reflect health service interventions rather than the wider influences on health.
A5. The University of Surrey was commissioned to produce a package of comparative statistics based on the outcome measures recommended in the feasibility study. Forty indicators were chosen, 18 for maternal and child health, three for mental health and the rest for other topics in adult health. The publication (Department of Health 1993a) contained indicator definitions, maps and scatter plots showing geographical variations, and tables presenting the rates, with corresponding observed numbers and confidence intervals when appropriate.

The Phase 3 work: ideal indicators of health outcomes

A6. In the third and current phase of the work on health outcomes a number of research institutions were commissioned to assist in developing a structured approach to identify indicators to cover a number of clinical topics. The prime contractor is the Unit of Health-Care Epidemiology, Department of Public Health and Primary Care, University of Oxford.

A7. The respective roles of the supporting organisations are as follows:

- Unit of Health-Care Epidemiology, University of Oxford, to provide epidemiological and managerial support to the Group and co-ordinate the input of the other agencies.
- CASPE Research, in London, to provide technical advice with regard to the indicators and their data sources, and prepare the detailed indicator specifications
- NHS Centre for Reviews and Dissemination, University of York, to produce reviews of the literature on the effectiveness and cost-effectiveness of relevant interventions.
- UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds to provide support in identifying measures and instruments to be used for assessing outcomes.

A8. In the previous work a key criterion for selection of indicators was the requirement for the work to be based on routinely available data. This practical constraint has meant that the recommended indicators were selected and opportunistic rather than an ideal set. This inevitably led, as the DoH acknowledged, to a bias towards outcomes which may be measurable now but which may not necessarily be those which are most appropriate and most needed. The aim of the third phase is to advise on and develop ‘ideal’ outcome indicators without confining recommendations to data which have been routinely available in the past.

A9. The initial task of the third phase of the work was to select clinical topics for detailed study. In order to ensure that the work would be manageable, and that the NHS would have the capacity to absorb the output, the CHOU decided to limit the activity to five clinical topics a year.
A10. A workshop to initiate the work which was attended by over 70 individuals representing a wide range of interests was held in January 1995. A report of the proceedings has been published (Goldacre and Ferguson 1995). The main aims of the workshop were:

- to identify the criteria which should be used to choose clinical topics for the Phase 3 work
- to suggest a list of potential clinical topics which workshop participants would like to be included in the Phase 3 work.

Mental illness scored highly against all the criteria and appeared on all the shortlists of topics to be addressed which were developed at the workshop.

A11. Following further consultation within and outside the DoH, the CHOU decided in June 1995 to include the following topics in the first two years of the Phase 3 work:

- Asthma
- Breast cancer
- Cataract
- Diabetes mellitus
- Fracture of neck of femur
- Incontinence
- Myocardial infarction
- Pregnancy and childbirth
- Severe mental illness
- Stroke.

Health outcome information

A12. For the purposes of the Group's work a health outcome was defined as a change in health or health related status which may be the result of the natural history of disease or the attributable effect of an intervention. An indicator was defined as an aggregated statistical measure, describing a specific group of people, compiled from measures or assessments made on individuals in the group.

A13. The Group was influenced in its work by considering the potential uses of outcome information, as follows:

- for decision-making by professionals and audit of their work, including:
  - meeting the needs of service users
  - undertaking statutory responsibilities
  - audit and management of professionals' practice
  - research
Severe Mental Illness Outcome Indicators

- for informing decisions about the strategic and operational development of services

- for comparisons of organisations in the delivery of services which may be:
  - provider based
  - population based

- for assessing progress towards standards or targets for health outcomes, agreed nationally or locally, which may be:
  - identified from the research literature
  - set by clinical and managerial decisions
  - informed by local service users.

A14. Current managerial interests which are relevant to the use of health outcome information include:

- The NHS goal 'to secure, through the resources available, the greatest improvement in the physical and mental health of people in England'
- audit of professional work and development of practice guidelines
- evidence-based commissioning
- involvement of local people, including minority groups, in the development of services.

A15. A crucial component of the work has been the development of a health outcome model (see Section 2) which has assisted the Group to review systematically all the factors which might be related to health outcomes.

A16. An important purpose of this work has been to recommend indicators which, if possible, would allow improvements in health and social function to be assessed alongside information used to measure service input. The particular focus has been to make recommendations about aggregated statistical information about people with severe mental illness which could be used to:

- enable the providers of care to review health outcomes
- make comparisons of health outcomes against locally agreed targets and/or between different places and/or over time.

A17. Information for outcome indicators may be obtained from continuous data collection systems but, when having continuously collected information is unnecessary, or when the cost or complexity of this is high, use should be made of sample survey techniques or periodic surveys. Nonetheless the vast majority of clinical care is delivered in routine rather than experimental practice. The assessment of its outcomes entails, by definition, the use of observational rather than experimental data.
A18. Health indicators are more likely to be successful if they fit naturally into the everyday work of professionals than when they have to be collected as a separate activity. The aim is to have indicators that are:

- Relevant and practicable because professionals use them everyday and will record them accurately.
- Reliable because they can be validated or cross checked from other sources.
- Responsive because they readily identify changes in the individual’s state of health.
- Research-based because there is a plausible link between processes of care and outcome.

A19. In common with the approach taken to other types of indicators by the NHS, the Group recognise that useful outcome indicators should be capable of identifying circumstances worthy of investigation, but that in themselves they may not necessarily provide answers to whether care has been ‘good’ or ‘bad’. In particular it is recognised that there may be difficulties in drawing causal conclusions - say, that a particular aspect of care caused a particular outcome - from indicators derived from non-experimental clinical settings.

A20. To be useful, work on ‘ideal’ outcome aspects needs to incorporate considerations of practicability. It is a time of rapid change in information technology. What may be feasible now in some places may not be feasible everywhere. What may not be practical today may become so in a year or two.
Severe Mental Illness Outcome Indicators
APPENDIX B: SEVERE MENTAL ILLNESS WORKING GROUP

B1. The Severe Mental Illness Working Group was formally constituted in January 1996 and met five times, completing its work in July 1997. The Report was completed in December 1997. The terms of reference were:

- For people with severe mental illness to advise on indicators of health outcomes, including physical and social wellbeing, of the prevention and treatment of the disorder.
- To make recommendations about the practicalities of the compilation and interpretation of the indicators, and to advise if further work is needed to refine the indicators and/or make them more useful.

B2. The membership of the Working Group and the staff of the supporting organisations are shown below. The Group included the major professional and managerial groups involved with severe mental illness as well as representatives of service users.

Chairman and members

<table>
<thead>
<tr>
<th>Psychi atrists</th>
<th>Paul Lelliott, Royal College of Psychiatrists</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Geraldine Strathdee, Sainsbury Centre for MH</td>
</tr>
<tr>
<td></td>
<td>Dily Jones, High Security Psychiatric Services</td>
</tr>
<tr>
<td>Psychologists</td>
<td>Geoff Shepherd, Sainsbury Centre for MH</td>
</tr>
<tr>
<td></td>
<td>John Hall, Oxfordshire Mental Healthcare</td>
</tr>
<tr>
<td>Nurse</td>
<td>Nicola Mahood, Manchester (unable to attend)</td>
</tr>
<tr>
<td>GP</td>
<td>Huw Lloyd, Colwyn Bay</td>
</tr>
<tr>
<td>Social work</td>
<td>Denise Platt, Assoc of Metropolitan Authorities</td>
</tr>
<tr>
<td></td>
<td>Jenny Bernard, City of Newcastle-Upon-Tyne</td>
</tr>
<tr>
<td></td>
<td>Gwen Ovshinsky, Hertfordshire</td>
</tr>
<tr>
<td>Researchers</td>
<td>David Meltzer, Cambridge Health</td>
</tr>
<tr>
<td>CEOs</td>
<td>Pamela Charlwood, Avon HA (Chairman)</td>
</tr>
<tr>
<td>DoH</td>
<td>Chris Heginbotham, formerly Riverside Mental HT</td>
</tr>
<tr>
<td>Voluntary bodies</td>
<td>Janet McGrae, National Schizophrenia Fellowship</td>
</tr>
<tr>
<td></td>
<td>Vivien Lindow, Survivors Network, Bristol</td>
</tr>
<tr>
<td></td>
<td>Suman Fernando, NAFSIYAT, London</td>
</tr>
</tbody>
</table>
Academic support and secretariat

Michael Goldacre, Alastair Mason and John Fletcher, University of Oxford
Robert Cleary and James Coles, CASPE Research, London
Alison Eastwood, NHS Centre for Reviews and Dissemination, University of York
Joanne Greenhalgh, UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds
Paul Lelliott, April 1997

EXISTING DEFINITIONS OF SMI

Proposals

C1. Goldman et al. (1981) proposed the following criteria:

- Diagnosis: According to DSM-III criteria, either:
  - organic brain syndrome
  - schizophrenia
  - paranoid and other psychoses
  - major affective disorders.

- Disability: Erosion of, or prevention of the development of, functional capacities in relation to three or more primary aspects of daily life:
  - personal hygiene and self-care
  - self-direction
  - interpersonal relationships
  - social transactions
  - learning
  - recreation
  - economic self-sufficiency.

- Duration: Most have required > three months hospitalisation in one year or > one year in preceding five years. Although some have required short-term hospitalisation (< three months) or have only received out-patient care.

C2. McLean and Liebowitz (1989) considered at least one of the following must be present:

- two or more years of contact with services
- depot prescribed
- ICD-9 classification 295 or 297
- three or more in-patient admissions in the last two years
- three or more day-patient episodes in the last two years
- DSM-III-R highest level of adaptive functioning in the past year = level 5 or less.
C3. The Department of Health (1995) proposed the following criteria be considered:

- Safety History of significant violence, self-harm or self-neglect or at risk of exploitation due to mental illness.
- In/formal help Need for intensive support in the community either from informal carers or from formal services such as more than one contact with specialist services per week, involvement of two or more agencies or subject to Section 117 of the Mental Health Act, Supervised Discharge or a Restriction Order.
- Diagnosis Presence of severe mental disorder including psychotic illness, severe neurotic illness, personality disorder, dementia, development disorder.
- Disability Significant impairment of functioning in role performance in one or more of occupation, family responsibility or accommodation; particularly where this has led to social isolation and/or difficulties with the activities of daily living. Indicators of this may include being in receipt of Disability Living Allowance, being homeless or requiring supported, sheltered accommodation.
- Duration Length of illness of greater than one year or likelihood of illness persisting; three or more admissions, or aggregate total of one year stay, in past five years.

C4. The Audit Commission (1994) defined three categories of people with mental illness in contact with secondary care services:

- Psychotic diagnosis, organic illness or injury and previous compulsory admission or aggregate one year stay in hospital in past five years or three or more admissions in past five years.
- Psychotic diagnosis, organic illness or injury or any previous admissions in past five years.
- No record of hospital admissions and no recorded psychotic diagnosis, organic illness or injury.

Summary

C5. In summary, all definitions which have been developed from the service provider perspective have included:

- certain diagnostic categories which would include ICD-10 categories FO, F2, F30, F31, F32 and F33
- some measure of **duration of illness** either a specified time since onset of illness or a specified period of hospitalisation
- some measure of **intensity of contact with services** usually specified as a certain time in hospital or a certain number of admissions over a given period.

**C6.** In addition, most definitions have included:

- statement about extent of disability as perceived by the user in terms of impairment of functioning in role performance.

**C7.** One definition has included:

- statement about risk posed, to others or self
- applicability of statutory powers to compel the patient to receive treatment.
SMI DEFINITION PILOT STUDY

Introduction

C9. In the absence of any widely accepted definition of severe mental illness, the Working Group proposed the following which it is recognised only takes into account the service provider perspective:

There must be a mental disorder as designated by a mental health professional (psychiatrist, mental health nurse, clinical psychologist, occupational therapist or mental health social worker) AND one or more of the following must apply:

- There must have been a score of 4 on at least one, or a score of 3 on at least two, of the HoNOS items 1-10 (excluding item 5 “physical illness or disability problems”) during the previous six months.
- Any admission in the past year under a treatment Section of the Mental Health Act.
- A total of six months in hospital, mental health residential care or day hospital or three admissions to hospital or day hospital over the past five years.
- Six months of continuous community care involving more than one worker or the need for such care if unavailable or refused.

C10. The aim of the pilot was to test the definition for its:

- Face validity: do mental health professionals from different disciplines find the criteria acceptable?
- Construct validity: do the criteria differentiate between groups of users which would be expected to contain different proportions with severe mental illness?
- Feasibility: are the criteria easy to apply?
- Redundancy: are all the criteria necessary to identify severe mental illness?

Method

C11. Piloting was conducted with the assistance of volunteer sites from the network of mental health services which have expressed interest in the work to develop the Health of the Nation Outcome Scales (HoNOS). These sites have either participated in one or more of the stages of the work to develop HoNOS or have had workers trained in its use. Thus although participants may not have been fully representative they were aware of HoNOS (which was an important component of the definition of SMI) and had some experience in its use. Returns were received from seven sites by the deadline date.
C12. The pilot was in two phases:

- **Consultation exercise** to gauge the acceptability of the criteria. Local co-ordinators circulated a brief questionnaire to representatives of all clinical disciplines which might be asked to apply the criteria. This enquired whether:
  - the language and wording of the criteria are acceptable
  - whether criteria are clearly stated
  - whether information to rate the criteria would be routinely available.

- **Field testing** which involved workers in sites applying the criteria to patients under their care and in a variety of settings.

**Results**

C13. Returns were received from 103 mental health workers in the seven sites:

- 60 mental health nurses
- 14 psychiatrists
- 7 social workers
- 9 clinical psychologists
- 12 occupational therapists
- 1 who did not state an affiliation.

C14. Exhibit C1 summarises the group's responses to the specific questions in the consultative exercise. As can be seen, the wording, language and clarity of the definition were acceptable to the great majority. There was less agreement that the necessary information to apply the definition would be available after a routine assessment; 40% thought either not or only gave a qualified affirmative. Although numbers for some groups were small, there were no discernable differences in the responses of the different professional groups; in particular no social worker, clinical psychologist or OT found the wording unacceptable.

C15. Content analysis of the comments received showed that:

- there is some unhappiness with the term designated
- there is a need to specify that the reference is to time in a psychiatric hospital
- there is a tension between doctors who want to use formal diagnoses and non-doctors who do not want to diagnose and the same tension arises over the use of the phrase mental disorder as opposed to mental illness
- some services do not collect HoNOS data routinely.
C16. Exhibit C2 summarises the characteristics of raters and 284 patients involved in the field test.

C17. Consistent with the experience of HoNOS field trials, the majority of raters (71% - n=201) were mental health nurses. There were very few ratings by clinical psychologists and none by occupational therapists. The patients were distributed across the five care settings although patients at their first contact (which excluded emergency assessments) were under-represented. One-fifth of patients (n=57) were not on CPA. Two-thirds of these were either inpatients (n=17) or day patients (n=18) and presumably workers considered that CPA level was to be assigned at discharge for patients already receiving intensive care in a hospital setting.

C18. According to the criteria, 235 (83%) of the patients would have been defined as having SMI. The distribution of these patients across care settings is shown in Exhibit C3; 89% of patients in residential settings, day care or receiving continuing community care met criteria compared with only 62% of patients who were receiving out-patient care or assessment. Exhibit C4 shows distribution, of patients who do and do not meet criteria, across levels of CPA; 96% of people on CPA levels 2 or 3 met criteria compared with 64% who were on level 1.

C19. Exhibit C5 shows the frequency with which each of the separate criteria which make up the definition of SMI were met. The commonest criterion to be met was that for being in continuous community care for the past six months or for needing that level of care (70% of sample). None of the other separate criteria were met by more than 40% of the sample and two (spending more than six months in residential care and being subject to detention under a treatment Section of the Mental Health Act) were met by fewer than 15%.

C20. Of the 235 patients who were defined as having SMI, 75 (32%) met one criterion, 62 (26%) met two, 49 (21%) met three, 31 (13%) met four, 15 (6%) met five and 3 (1%) met six (3 [1%] had some missing data). Exhibit C6 shows the frequencies with which two separate criteria were met by the same patient. There was a direct relationship between the number of criteria met by people with a mental disorder and mean total HoNOS scores. HoNOS scores for patients meeting three (12.6; 95% ci = 10.4 - 14.7) and four (13.1; 10.7-15.5) criteria were significantly higher than for patients meeting none (8.2; 6.6 - 9.8), one (7.8; 6.3-9.3) or two (9.7; 8.1-11.2).

C21. The relationship between the mean number of criteria met by people with mental disorder (the ‘SMI score’) and the care setting of patients was also as anticipated in that scores fell progressively with level of care intensity. Thus patients in hospital (3.0 criteria; 95% ci = 2.7-3.4) residential care (3.2; 2.5-3.9) and day hospital (2.4; 2.0-2.8) had significantly higher SMI scores than those receiving community care (1.9; 1.7-2.2), continuous out-patient care (1.3; 1.0-1.7) or having their first contact (1.3; 0.7-1.8).
C22. Likewise, patients on the highest tier of CPA - level 3 - had significantly higher ‘SMI scores’ (3.4; 95% ci = 3.2-3.7) than those on level 1 (1.3; 1.0-1.6) or level 2 (1.9; 1.6-2.1).

C23. To test for redundancy of criterion items, patients who met the definition for SMI were removed as they met one criterion in descending order of frequency with which criteria were met. Thus 188 patients were removed because they had received, or needed, six months of continuous community care, a further 36 because they met the criterion for HoNOS score, a further nine because they had spent six months or more in hospital, and the final two because they had three or more admissions. Thus no patients met the definition of SMI solely because they had been subject to a treatment Section of the Mental Health Act, spent six months continuously in residential care or in day care.

**Comment and recommendations**

C24. The wording and language of the definition were acceptable to the mental health care workers in secondary care services in the study. Minor re-wording would improve it further.

C25. Some workers did not routinely have the necessary information to apply the definition; the most common reason was that HoNOS scores are not always rated.

C26. Using the definition to categorise patients was consistent with other proxy measures of SMI, i.e. CPA level and intensity of care. But there was a preponderance of people receiving high intensity care and some groups of patients, particularly those who would be expected to have a high proportion without SMI, were either under-represented (e.g. first contacts) or absent (e.g. patients being treated in primary care).

C27. When the definition was used categorically, the criterion relating to receiving, or needing, continuous community care predominated and others were redundant (been subject to a treatment Section of the Mental Health Act, spent six months continuously in residential care or in day care).

C28. There is some value in adding the SMI criteria to create a dimensional SMI score.
C29. As a result of the study and further discussion by the Group it is recommended that the definition of severe mental illness, which only includes a service provider perspective, be amended as follows:

- There must be a mental disorder as designated by a mental health professional (psychiatrist, mental health nurse, clinical psychologist, occupational therapist or mental health social worker) AND EITHER

- There must have been a score of 4 (severe/very severe problem) on at least one, or a score of 3 (moderately severe problem) on at least two, of the HoNOS items 1-10 (excluding item five 'physical illness or disability problems') during the previous six months OR

- There must have been a significant level of service usage over the past five years as shown by:
  - a total of six months in a psychiatric ward or day hospital, or
  - three admissions to hospital or day hospital, or
  - six months of psychiatric community care involving more than one worker or the perceived need for such care if unavailable or refused.

C30. No detailed work has been done as yet to obtain a service user perspective and the service providers contacted in the study have only been a limited sample. Particular issues arise with relation to:

- service users from different ethnic groups
- atypical presentations which are not diagnosed as mental disorders
- behaviour wrongly diagnosed as mental disorder
- care from primary care teams
- assessments made at first contact with mental health services.

C31. Further work needs to be commissioned to:

- test the provider based definitions with more providers including those from ethnic minorities
- work up a definition from the service user perspective
- attempt to bring all the work together to obtain a definition incorporating both perspectives.
**EXHIBIT C1:** RESPONSES OF MENTAL HEALTH CARE WORKERS TO THE DEFINITION OF SMI

<table>
<thead>
<tr>
<th></th>
<th>Acceptable/Yes</th>
<th>Acceptable/Yes but qualified</th>
<th>Unacceptable/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are the wording and language acceptable?</td>
<td>86 (88%)</td>
<td>7 (7%)</td>
<td>5 (5%)</td>
</tr>
<tr>
<td>Are the criteria clearly stated?</td>
<td>89 (92%)</td>
<td>4 (4%)</td>
<td>4 (4%)</td>
</tr>
<tr>
<td>Would you have the necessary information following a routine assessment?</td>
<td>57 (60%)</td>
<td>19 (20%)</td>
<td>19 (20%)</td>
</tr>
</tbody>
</table>
## EXHIBIT C2: CHARACTERISTICS OF RATERS AND PATIENTS (N=284)

<table>
<thead>
<tr>
<th></th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Profession of rater(^1)</strong></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>201 (71%)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>41 (14%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>34 (12%)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>8 (3%)</td>
</tr>
<tr>
<td><strong>Age of patient</strong></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>241 (85%)</td>
</tr>
<tr>
<td>65 or over</td>
<td>43 (15%)</td>
</tr>
<tr>
<td><strong>Setting at time of rating</strong></td>
<td></td>
</tr>
<tr>
<td>In-patient</td>
<td>61 (22%)</td>
</tr>
<tr>
<td>Residential care</td>
<td>22 (8%)</td>
</tr>
<tr>
<td>Day care</td>
<td>49 (17%)</td>
</tr>
<tr>
<td>Community care</td>
<td>83 (29%)</td>
</tr>
<tr>
<td>Out-patient care</td>
<td>51 (18%)</td>
</tr>
<tr>
<td>First contact</td>
<td>15 (5%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>3 (1%)</td>
</tr>
<tr>
<td><strong>CPA level at time of rating</strong></td>
<td></td>
</tr>
<tr>
<td>Not on CPA</td>
<td>57 (20%)</td>
</tr>
<tr>
<td>1</td>
<td>67 (24%)</td>
</tr>
<tr>
<td>2</td>
<td>70 (25%)</td>
</tr>
<tr>
<td>3</td>
<td>87 (30%)</td>
</tr>
<tr>
<td>Missing data</td>
<td>3 (1%)</td>
</tr>
</tbody>
</table>

\(^1\) Many raters made ratings on more than one patient
### EXHIBIT C3: DISTRIBUTION OF PATIENTS WHO DO AND DO NOT MEET CRITERIA FOR SMI ACROSS CARE SETTINGS

<table>
<thead>
<tr>
<th>Type of care</th>
<th>SMI (%)</th>
<th>Not SMI (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-patient</td>
<td>54 (90%)</td>
<td>6 (10%)</td>
</tr>
<tr>
<td>Residential care</td>
<td>18 (82%)</td>
<td>4 (18%)</td>
</tr>
<tr>
<td>Day hospital</td>
<td>45 (94%)</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Community care</td>
<td>72 (88%)</td>
<td>10 (12%)</td>
</tr>
<tr>
<td>Out-patient care</td>
<td>35 (70%)</td>
<td>15 (30%)</td>
</tr>
<tr>
<td>First contact</td>
<td>5 (30%)</td>
<td>10 (70%)</td>
</tr>
</tbody>
</table>

### EXHIBIT C4: DISTRIBUTION OF PATIENTS WHO DO AND DO NOT MEET CRITERIA FOR SMI ACROSS LEVELS OF CPA

<table>
<thead>
<tr>
<th>CPA Level</th>
<th>SMI (%)</th>
<th>Not SMI (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not on CPA</td>
<td>41 (75%)</td>
<td>14 (25%)</td>
</tr>
<tr>
<td>CPA level 1</td>
<td>43 (64%)</td>
<td>24 (36%)</td>
</tr>
<tr>
<td>CPA level 2</td>
<td>66 (96%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>CPA level 3</td>
<td>83 (97%)</td>
<td>3 (3%)</td>
</tr>
</tbody>
</table>
## EXHIBIT C5: FREQUENCY WITH WHICH EACH OF THE CRITERIA FOR MEETING SMI, WERE MET

<table>
<thead>
<tr>
<th>CRITERION</th>
<th>YES</th>
<th>NO</th>
<th>MISSING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental disorder present During past 6 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. One or more HoNOS item rated at 4</td>
<td>71 (25%)</td>
<td>212 (75%)</td>
<td>1</td>
</tr>
<tr>
<td>2. Two or more HoNOS items rated at 3</td>
<td>58 (20%)</td>
<td>224 (79%)</td>
<td>2</td>
</tr>
<tr>
<td>1 and/or 2</td>
<td>107 (38%)</td>
<td>176 (62%)</td>
<td>1</td>
</tr>
<tr>
<td>A1. in continuous community care</td>
<td>180 (63%)</td>
<td>102 (36%)</td>
<td>2</td>
</tr>
<tr>
<td>A2. If no to A1, need for such support</td>
<td>21 (7%)</td>
<td>81</td>
<td></td>
</tr>
<tr>
<td>During past one year B. Subject to treatment Section of MHA in the past year</td>
<td>31 (11%)</td>
<td>249 (88%)</td>
<td>4</td>
</tr>
<tr>
<td>During past 5 years C. 3 or more admissions to psychiatric ward</td>
<td>90 (32%)</td>
<td>194 (68%)</td>
<td></td>
</tr>
<tr>
<td>D. &gt; 6 months in hospital</td>
<td>75 (26%)</td>
<td>208 (73%)</td>
<td>1</td>
</tr>
<tr>
<td>E. &gt; 6 months in mental health residential accommodation</td>
<td>39 (14%)</td>
<td>245 (86%)</td>
<td></td>
</tr>
<tr>
<td>F. &gt; 6 months at psychiatric day hospital</td>
<td>49 (17%)</td>
<td>234 (82%)</td>
<td>1</td>
</tr>
</tbody>
</table>

## EXHIBIT C6: FREQUENCIES WITH WHICH TWO INDIVIDUAL CRITERIA WERE MET BY THE SAME PATIENT

<table>
<thead>
<tr>
<th>HoNOS plus</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>HoNOS plus</td>
<td>107</td>
<td>69</td>
<td>13</td>
<td>36</td>
<td>29</td>
<td>14</td>
</tr>
<tr>
<td>A. Continuing community care</td>
<td>201</td>
<td>24</td>
<td>79</td>
<td>53</td>
<td>34</td>
<td>43</td>
</tr>
<tr>
<td>B. Mental Health Act</td>
<td>31</td>
<td>18</td>
<td>18</td>
<td>7</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>C. 3+ admissions</td>
<td>90</td>
<td>46</td>
<td>19</td>
<td>26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. &gt; 6 months in hospital</td>
<td>29</td>
<td>18</td>
<td>20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E. &gt; 6 months in res care</td>
<td>39</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F. &gt; 6 months in day care</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX D: HEALTH OF THE NATION OUTCOME SCALES (HONOS) FOR SEVERE MENTAL ILLNESS

Summary of rating instructions:

1. Rate each scale in order from 1 to 12.
2. Do not include information rated in an earlier item.
3. Rate the most severe problem that occurred during the period rated.
4. All scales follow the format:
   0 = no problem.
   1 = minor problem requiring no action.
   2 = mild problem but definitely present.
   3 = moderately severe problem.
   4 = severe to very severe problem.
   9 = not known/not applicable.

Scale 1: Overactive, aggressive, disruptive behaviour

Include such behaviour due to any cause, e.g. drugs, alcohol, dementia, psychosis, depression, etc.
Do not include bizarre behaviour, rated at Scale 6.

0 No problems of this kind during the period rated.
1 Some irritability, quarrels, restlessness etc.
2 Includes occasional aggressive gestures, pushing or pestering others; threats or verbal aggression; lesser damage to property (e.g. broken cup, window); marked overactivity or agitation.
3 Physically aggressive to others or animals (short of rating 4); persistently threatening manner; more serious overactivity or destruction of property.
4 At least one serious physical attack on others or on animals; destructive of property (e.g. fire-setting); persistent serious intimidation or obscene behaviour.

Scale 2: Non-accidental self-injury

Do not include accidental self-injury (due e.g. to dementia or severe learning disability); the cognitive problem is rated at Scale 4 and the injury at Scale 5.
Do not include illness or injury as a direct consequence of drug/alcohol use rated at Scale 3; (e.g. cirrhosis of the liver or injury resulting from drunk driving are rated at Scale 5).

0 No problem of this kind during the period rated.
1 Fleeting thoughts about ending it all but little risk; no self-harm.
2 Minor risk during period; includes non-hazardous self-harm, e.g. wrist-scratching.
3  Moderate to serious risk of deliberate self-harm; includes preparatory acts e.g. collecting tablets.
4  Serious suicidal attempt and/or serious deliberate self-injury during period.

Scale 3 : Period-drinking or drug taking

Do not include aggressive/destructive behaviour due to alcohol or drug use, rated at Scale 1. Do not include physical illness or disability due to alcohol or drug use, rated at Scale 5.

0  No problem of this kind during the period rated.
1  Over-indulgence but within social norm.
2  Loss of control of drinking or drug-taking, but not seriously addicted.
3  Marked dependence on alcohol or drugs with frequent loss of control, drunk driving, etc.
4  Incapacitated by alcohol/drug problems.

Scale 4 : Cognitive problems

Include problems of memory, orientation and understanding associated with any disorder; learning disability, dementia, schizophrenia, etc. Do not include temporary problems (e.g. hangovers) resulting from drug/alcohol use, rated at Scale 3.

0  No problem of this kind the period rated.
1  Minor problems with memory or understanding, e.g. forgets names occasionally.
2  Mild but definite problems, e.g. has lost the way in a familiar place or failed to recognise a familiar person; sometimes mixed up about simple decisions.
3  Marked disorientation in time, place or person, bewildered by everyday events; speech is sometimes incoherent; mental slowing.
4  Severe disorientation, e.g. unable to recognise relatives, at risk of accidents, speech incomprehensible; clouding or stupor.

Scale 5 : Physical illness or disability problems

Include illness or disability from any cause that limits or prevents movement, or impairs sight or hearing, or otherwise interferes with personal functioning. Include side-effects from medication; effects of drug/alcohol use; physical disabilities resulting from accidents or self-harm associated with cognitive problems, drink-driving, etc. Do not include mental or behavioural problems rated at Scale 4.

0  No physical health problem during the period rated.
1  Minor health problem during the period e.g. cold, non-serious fall, etc.
2 Physical health problem imposes mild restriction on mobility and activity.
3 Moderate degree of restriction on activity due to physical health problem.
4 Severe or complete incapacity due to physical health problem.

Scale 6: Problems associated with hallucinations and delusions

Include hallucinations and delusions irrespective of diagnosis. Include odd and bizarre behaviour associated with hallucinations or delusions. Do not include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions, rated at Scale 1.

0 No evidence of hallucinations or delusions during the period rated.
1 Somewhat odd or eccentric beliefs not in keeping with cultural norms.
2 Delusions or hallucinations e.g. voices, visions are present, but there is little distress to patient or manifestation in bizarre behaviour, i.e. clinically present but mild.
3 Marked preoccupation with delusions or hallucinations, causing much distress and/or manifested in obviously bizarre behaviour, i.e. moderately severe clinical problem.
4 Mental state and behaviour is seriously and adversely affected by delusions or hallucinations, with severe impact on patient and/or others.

Scale 7: Problems with depressed mood

Do not include overactivity or agitation, rated at Scale 1. Do not include suicidal ideation or attempts, rated at Scale 2. Do not include delusions or hallucinations, rated at Scale 6.

0 No problems associated with depressed mood during the period rated.
1 Gloomy; or transient mood changes.
2 Mild but definite depression and distress: e.g. feelings of guilt; sleep disturbance; loss of appetite; loss of self-esteem.
3 Depression with inappropriate self-blame, preoccupied with feelings of guilt.
4 Severe or very severe depression, with guilt or self-accusation.
Scale 8: Other mental and behavioural problems

Rate only the most severe clinical problem not considered at items 6 and 7 as follows. Specify the type of problem by entering the appropriate letter: A phobic; B anxiety; C obsessive-compulsive; D stress; E dissociative; F somatoform; G eating; H sleep; I sexual; J other; specify.

0 No evidence of any of these problems during period rated.
1 Minor non-clinical problems.
2 A problem is clinically present, but there are relatively symptom-free intervals and patient/client has a degree of control, i.e. mild level.
3 Constant preoccupation with problem. Occasional severe attack or distress, with loss of control e.g. has to avoid anxiety provoking situations altogether, call in a neighbour to help, etc.
4 Severe, persistent problem dominates most activities.

Scale 9: Problems with relationships

Rate the patient’s most severe problem associated with active or passive withdrawal from social relationships, and/or non-supportive, destructive or self-damaging relationships.

0 No significant problems during the period.
1 Minor non-clinical problem.
2 Definite problems in making or sustaining supportive relationships: patient complains and/or problems are evident to others.
3 Persisting major problems due to active or passive withdrawal from social relationships that provide little or no comfort or support.
4 Severe and distressing social isolation due to inability to communicate socially and/or withdrawal from social relationships.
Scale 10: Problems with activities of daily living

Rate the overall level of functioning in activities of daily living (ADL): e.g. problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development, etc. Include any lack of motivation for using self-help opportunities, since this contributes to a lower overall level of functioning. Do not include lack of opportunities for exercising intact abilities and skills, rated at Scales 11-12.

0 No problems during period rated; good ability to function in all areas.
1 Minor problems only; e.g. untidy, disorganised.
2 Self-care adequate, but major lack of performance of one or more complex skills (see above).
3 Major problems in one or more area of self-care (eating, washing, dressing, toilet) as well as major inability to perform several complex skills.
4 Severe disability or incapacity in all or nearly all areas of self-care and complex skills.

Scale 11: Problems with living conditions

Rate the most severe problem with the quality of living conditions and daily domestic routine. Are the basic necessities met (heat, light, hygiene)? If so, is there help to cope with disabilities and a choice of opportunities to use skills and develop new ones? Do not rate the level of functional disability itself, rated at Scale 10.

N.B. Rate patient’s usual accommodation. If in acute ward, rate the home accommodation. If information not available, rate 9.

0 Accommodation and living conditions are acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.
1 Accommodation is reasonably acceptable although there are minor or transient problems e.g. not ideal location, not preferred option, doesn’t like the food etc.
2 Significant problems with one or more aspects of the accommodation and/or regime; e.g. restricted choice; staff or household have little understanding of how to help use or develop new or intact skills.
3 Distressing multiple problems with accommodation; e.g. some basic necessities absent; housing environment has minimal or no facilities to improve patient’s independence.
4 Accommodation is unacceptable; e.g. lack of basic necessities, patient is at risk of eviction, or ‘roofless’, or living conditions are otherwise intolerable making patient’s problems worse.
Scale 12: Problems with occupation and activities

Rate the most severe problem with quality of day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, access to supportive facilities, e.g. staffing and equipment of day centres, workshops, social clubs, etc. Do not rate the level of functional disability itself, rated at Scale 10.

N.B. Rate patient's usual situation. If in acute ward, rate activities during period before admission. If information not available, rate 9.

0 Patient's day-time environment is acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.
1 Minor or temporary problems e.g. late giro cheques, reasonable facilities available but not always at desired times, etc.
2 Limited choice of activities or there is a lack of reasonable tolerance e.g. unfairly refused entry to public library or baths, etc; or handicapped by lack of a permanent address or insufficient carer or professional support; or unhelpful day setting available but for very limited hours.
3 Marked deficiency in skilled services available to help minimise level of existing disability; no opportunities to use intact skills or add new ones; unskilled care difficult to access.
4 Lack of opportunity for daytime activities makes patient's problems worse.
SCOPE

E1. The Working Group commissioned three short literature reviews related to specific effectiveness issues:

- long-term outcomes in severe mental illness
- cross cultural outcomes for severe mental illness
- organisation of services for severe mental illness.

LONG-TERM OUTCOMES IN SEVERE MENTAL ILLNESS

Introduction

E2. The aim of this Section is to examine the literature assessing the long-term outcome of severe mental illness. An initial minimum value of five years was taken to eliminate ‘short-term’ outcomes, but the emphasis was on identifying long-term outcomes over decades of years rather than a few years. As with all longitudinal studies, there are a number of methodological issues which should be borne in mind when interpreting the results. In particular, there are difficulties in attributing change to specific interventions, given potential changes in other related factors such as organisational structures over the time of evaluation. Notwithstanding these difficulties, longitudinal information can provide useful insight into the potential for relapse in the long-term, which many short-term studies of interventions overlook.

Quality of available evidence

E3. The majority of the evidence looking at the long-term outcomes of people with severe mental illness focuses on schizophrenia. There are a number of studies looking at longer term outcomes of specific interventions, but no review work was identified which has synthesised these results. Very few studies were identified which evaluated outcome over decades rather than years.

E4. There are methodological difficulties specific to long-term retrospective studies. Few such studies evaluate the quality of retrospective data collection instruments. There is a need for further research on the validation of instruments.

Results

E5. The concepts, methods and results of long-term studies are complex. However, in general, studies suggest that for people diagnosed as having schizophrenia there is an early 5-10 years of deterioration, then a plateau. Within this period...
of relative stability there will be acute relapses, but these should resolve to the earlier stable level (Abrahamson 1993).

E6. The long course of hospitalisation for people with schizophrenia has been examined, both for the risk of re-hospitalisation and the change over time (Eaton et al. 1992a; Eaton et al. 1992b). The authors state that there have been a number of studies of the course and outcome of schizophrenia, but the vast majority have been restricted to one or two years follow-up. In their first study, Eaton et al. (1992a) found that re-hospitalisation after the initial episode ranged from 50-80% after follow-up of up to twenty years. The survival curve for duration in the community without hospitalisation drops sharply up to two and three years post-discharge and after about 15 years is approximately flat. Further, they found that early age at onset led to a higher risk of re-hospitalisation which overshadowed the effect of male gender or ‘never-married’.

E7. In the second study Eaton et al. (1992b) looked at changes over time. They distinguished between the heterogeneity of patients at initial hospitalisation, which led to variations in the course of the disease; and the heterogeneity that develops over time as episodes of hospitalisation occur. They found that episodes cluster earlier in treatment for schizophrenia, which suggests a progressive amelioration rather than deterioration. They estimate that each additional period of hospitalisation leads to a reduction in the risk of further hospitalisation by approximately 10%. However, it is difficult to attribute these results to any specific aspect of treatment, and there were a number of organisational changes over the time period of the study.

E8. Leff et al. (1992) report on five-year follow-up findings for patients in eight centres across the world in the International Pilot Study of Schizophrenia. They found considerable variation between countries in both social and clinical outcome. The centres of Agra and Ibadan had significantly better outcomes than those of the centres in ‘developed countries’. Ohaeri (1993) found relatively good long-term outcomes for patients whose schizophrenia had been treated in Nigeria, which ‘support previous reports indicating fairly good outcome of schizophrenia in developing countries.’

E9. Marneros et al. (1992) compared the long-term outcome of people with schizophrenia, affective and schizoaffective disorders. They found that schizophrenic disorders had a worse outcome than schizoaffective disorders which in turn had a worse outcome than affective disorders. The outcome for schizoaffective and affective disorders was more similar, the gap between schizoaffective and schizophrenic disorders being larger. However, they point out the methodological difficulties in assessment, due to variations in definition. They believe that the results are comparable with other studies if the definitional variations are taken into account.
E10. A number of studies have examined the long-term outcome of specific interventions. For example, Tarrier et al. (1994) assessed the long-term effects of family intervention on schizophrenic relapse, by following forty patients with schizophrenia who had participated in a family intervention trial and had not experienced relapse at two years after discharge from their index admission. They evaluated patients in the family intervention group and control groups of both high and low expressed emotion at up to eight years after discharge. At eight years, the number of relapses in the family intervention group was significantly lower than those in the high expressed emotion group. The number of relapses in the low expressed emotion group was similar to that of the family intervention, but not quite significantly lower than those in the high expressed emotion group.

E11. Gmur (1992) compared the outcomes of patients with schizophrenia treated either at a night clinic or hospital. The population of the study was selective due to the desire to evaluate the impact of the night clinic, but the patients (46 in each group) were followed-up for 12 years. At that time nearly 10% had died, all from destructive acts. The psychopathology of 1/3 was inconspicuous, 1/5 was conspicuous to a psychiatrist and 1/4 was conspicuous to a lay person. The majority of patients were on disability pension, few were in work appropriate to their training and experience. There was a marked decrease in the number and duration of overt phases and hospital stays over time. The study also found a significantly greater reduction in hospitalisations in the patients treated at the night clinic compared to those treated in hospital.

E12. In the Epidemiological Needs Assessment (Wing 1994), one study was identified which evaluated the outcome of community psychiatric nursing compared to conventional out-patient treatment at seven year follow-up (Burns et al. 1991). ‘Treatment differences persisted for two years beyond the original study but few differences were found at follow-up’ (Wing 1994).

Conclusions

E13. There is limited evidence on the long-term outcome of severe mental illness. The majority of evidence relates to people diagnosed with schizophrenia, and suggests a relatively optimistic long-term outcome in terms of additional morbidity and relapse, given initial severity and treatment. However, few studies were identified which assessed outcome after decades of follow-up.

E14. The published work has implications for the outcomes project. It raises the following questions:

- How can long-term outcome indicators be established in practice?
- How would data for long-term indicators be collected?
- How would data related to the same patient be linked?
- How would indicators be interpreted even if the data could be collected?
CROSS-CULTURAL OUTCOMES IN SEVERE MENTAL ILLNESS

Introduction

E15. This Section examines the evidence on cross-cultural outcomes in severe mental illness. There are difficulties in defining ‘culture’. As Fernando (1991) states: ‘in a broad sense, the term culture is applied to all features of an individual’s environment, but generally refers to its non-material aspects that the person holds in common with other individuals forming a social group. For example, it refers to child rearing habits, family systems, and ethical values or attitudes common to a group’. The vagueness of the definition has meant that culture is frequently confused with race, or ethnicity. Consequently, for the purpose of this document, ‘cross-cultural’ was taken to include comparisons across cultures, race and ethnicity as labelled in the literature. Attention has been focused on cross-cultural outcomes within the United Kingdom. Comparison between countries would be confounded by different health care systems and have questionable relevance to the provision of services in this country.

E16. The issue of alcohol-related disorders has been excluded from this work, although there is evidence of cross-cultural variation, for example between Indian Sikh and white men (Cochrane and Sashidharan 1996).

Quality of available evidence

E17. There is little evidence in the literature evaluating cross-cultural outcomes in the treatment of mental illness. There is a reasonable literature focused on variations in incidence and prevalence between ethnic minorities and the ‘mainstream white’ population. This literature examines the possible explanations for these variations.

Results

E18. Cochrane and Sashidharan (1996) have reviewed the evidence on mental health and ethnic minorities. They report the well documented excess of diagnosed schizophrenia in Britain’s African Caribbean population compared to the white population. Summarising the research they identify six points:

- There is an elevated rate of the diagnosis of schizophrenia in the African-Caribbean population compared to whites, which is of the order of three to five times.
- There is no evidence of such elevated rates anywhere else in the world.
- This increased risk is maintained in second generation immigrants.
- African-Caribbeans with schizophrenia are more likely than whites to be detained under the Mental Health Act and have police involvement.
There is some evidence that this is most prominent in African-Caribbean men born in the 1950's or early 1960's.

There is evidence of a poorer course and outcome of schizophrenia in Britain's black population than among whites. Black patients are more likely to be re-admitted, have longer hospital stays, have more residual symptoms and poorer social outcomes, and are given high intensity treatment such as higher neuroleptic doses and higher rates of ECT. Further, follow-up care may be lacking in quantity and quality.

**E19.** Cochrane and Sashidharan (1996) found that the incidence of the diagnosis of schizophrenia in Asian patients is similar to that in whites, but they have a better course and outcome following first admission such as fewer re-admissions and residual symptoms, and better social adjustment. Conversely they identified a much higher than expected rate of suicide among young married women from the Indian subcontinent. They also found that both the Hong Kong Chinese population and the Pakistani and Bangladeshi community in Britain have lower treated prevalence rates than whites. The psychological morbidity rates in the Hong Kong Chinese community are also low, however for the Pakistani-born population they are equivalent to that of the whites.

**E20.** The Irish represent the largest single foreign born group in Britain, but are seldom treated as a distinct ethnic group in the research literature (Cochrane and Sashidharan 1996). Williams (1992) evaluated the health of the Irish in Britain, but only in terms of incidence rather than outcomes of treatment. He concluded that the higher prevalence of schizophrenia in terms of identified cases in Ireland is not due to higher incidence, but rather to the collapse of community care. A community survey found the psychological morbidity of Irish immigrants to be lower than that of both Irish and English natives. However, psychiatric admissions in England are higher among Irish immigrants than natives, although the Irish immigrant rates in England are lower than rates in Ireland. One explanation of this is both positive and negative selection in immigrants: positive selection in those who are likely to be included in community surveys (hence low morbidity) and negative in those who are likely to be in temporary or institutional accommodation and thus excluded from community surveys but with a high psychiatric admission rate.

**E21.** One explanation for the variation between ethnic minorities and whites is that the voluntary sector organisations may be less acceptable to ethnic minorities. There is some evidence from the US that ethnic specific services are better at engaging ethnic minority clients but do not necessarily produce better outcomes. However, the feasibility and desirability of providing ethnically separate services is questionable (Cochrane and Sashidharan 1996). In London, the TULIP voluntary organisation set up an outreach service to help people who were caught in a cycle of hospitalisations, and whose severe mental distress was compounded by their homelessness and racial prejudice. Even though the outreach team was not developed exclusively for ethnic
minority groups, one aim is to make the service accessible to them. Initial results suggest that such intensive community support can engage people from a broad range of cultural backgrounds (Gauntlett et al. 1995).

Discussion

E22. ‘Race’ is frequently identified as an explanatory factor in trials of interventions for mental illness. As Ahmad et al. (1996) point out: “the uncritical approach to ‘race’, ‘ethnicity’ and ‘culture’ in epidemiological studies leads to confusion and misinformation. The use of these categories as independent variables underplays the significance of socio-economic conditions and health services related factors.”

E23. Sashidharan and Francis (1993) examine the evidence used to argue the higher prevalence of diagnosed mental illness (in particular schizophrenia) amongst certain ethnic groups, in particular African-Caribbean. They question the assumptions made, and point out the methodological flaws in epidemiological studies. This includes the measurement of numerators; diagnosis, and denominators, identification of the population at risk, in the calculation of rates; as well as ignoring the confounding effects of a variety of socio-demographic factors. The authors conclude that “by choosing an arbitrary and theoretically unsound division across ‘ethnicity’ as the independent variable in research in this area, much of which is unsatisfactory and invalid, psychiatry has become a powerful vehicle for articulating ideas about race rather than distress, disease or illness.”

E24. Alladin (1992) argues that cross-cultural variations are not due to pathogenic variations, but rather institutional racism. He highlights the inadequacies of clinical psychological models in general and specifically for ethnic minorities. It is not culture, nor ethnicity, but racism that is the problem.

E25. Fernando (1991) states that there are differences between the Western and Eastern/African concepts of mental health which need to be taken into consideration. ‘Although concepts of health and disease are largely determined by culture, a true picture of cross-cultural differences is distorted by the imposition of racist value judgements of the constituents of cultural systems, including the diverse ways in which disease and health are perceived, analysed and dealt with.’

E26. Doyal and Gough (1991) argue that severe mental illness involves a loss of autonomy, and ‘the fact that the reasons for such loss or the way in which individuals interpret them might be culturally variable does nothing to counter the claim that its symptoms lead to the same types of disability across cultures’. They go on to conclude that despite problems in diagnosis and symptoms across cultures, ‘careful comparative research has shown that in all cultures serious mental illness impairs social participation. This is revealed by
the common core of disabling symptoms found by all the studies to underly these variations in experience.’ Further: ‘valid comparisons can be drawn about the incidence of disablement accompanying diagnosed schizophrenia in different societies.’ To this end they state that international taxonomies of mental disorder such as ICD and DSM-III have made steps towards operationalising the cross-cultural diagnosis of mental disorder, and that, ‘using these diagnostic categories, comparisons can be made of the impairments to autonomy across countries and groups’. In contrast Fernando (1991) states that ‘the present systems of classification used in Western psychiatry, particularly the ICD-9 and DSM-III, are ethnocentric ones tied to Western culture’.

Conclusions

E27. There are variations in incidence and prevalence, as well as outcome for people with severe mental illness. The reasons for these differences have been ascribed to variations between ethnic groups, in particular African-Caribbean and Asian ethnic minorities compared to whites. However, it would appear that these differences are not due to inherent pathogenic differences in different cultures, but rather to socio-economic factors and the impact of culture on expressions and beliefs about health. Therefore it is difficult and possibly theoretically flawed to attempt to disentangle cross-cultural variations as a factor to look at in isolation.

E28. It has been argued by some that an ideal service for ethnic minorities would be one where specific needs would be addressed, for example with service users being able to speak in their own language, and attention being paid to cultural variations in expressions of distress but without stereotyping (Cochrane and Sashidharan 1996). As Fernando (1991) states ‘socio-cultural dimensions are not mere contexts for emotional expression but are primary determinants of affect and integral to their very constitution’.

E29. The implications of this work for the outcome project are complex. There are large variations in outcomes for different cultural groups, and there may well be certain aspects which it would be useful to monitor such as the high rate of suicide among young Indian women. However, from this work it is clear that the measurement of cross-cultural variation in outcomes will be highly influenced by social structure or ‘racialisation’ of society and psychiatry so that interpretation will be very difficult.
THE ORGANISATION OF MENTAL HEALTH SERVICES

Introduction

E30. The organisation of mental health services determines inter alia in which setting services are provided, and who provides these services. There is a trend away from institutionalised care towards care in the community, which has implications for the applicability of previous service evaluation. This is particularly true in the provision of residential care for the long-term mentally ill. The move towards community care means that those patients who continue to be treated in an institutional setting represent those with the most severe difficulties. As hospitals reduce in size or close down, patients with severe difficulties ‘block’ the available beds either in mental or in general hospitals, which can lead to premature discharge without adequate support, which in turn can lead to repeated acute admissions in the future.

Quality of available evidence

E31. A number of existing reviews have examined the organisation of services (Conway et al. 1994a; Wing 1994). In general, there is very little rigorous evidence available in the literature to address the broad issue of the organisation of mental health services.

E32. Conway and colleagues (1994a) evaluated the evidence of effectiveness of different forms of staff and service organisation in mental health services. The review was restricted to studies of adult mental health, focusing on the 16-65 age group. Few well conducted Randomised Controlled Trials (RCT) were identified. Consequently, although their emphasis was on RCTs, other study designs were included if their focus was on evaluation. They found that most evaluations were short-term, providing limited insight into the long-term effectiveness of differing settings. Further, evaluations of specific components in isolation will not necessarily take account of the impact of other complementary services.

E33. In the Epidemiological Needs Assessment, Wing (1994) found very little evidence relating to setting types and methods of intervention. The quality of evidence identified was graded according to the design of the study. Evidence from RCTs was identified to support targeted alternatives to acute admissions in some districts, as well as targeted hostel-wards based on one small study. Other evidence based on uncontrolled experiments or consensus opinion pointed towards the value of liaison in both general practice and other specialties, hospital closure, sheltered community and day care.
Results

E34. Conway and colleagues (1994a) have noted that there has been a trend for specialist staff to move into primary care settings. This move is associated with shifts in working practice, in particular community psychiatric nurses are often isolated from the specialist team, and their caseloads have increased with mainly less seriously ill patients such that their contact with psychotic and seriously ill patients has reduced. Similar findings were reported by Wing (1994).

E35. Furthermore, in those cases where specialist teams have been integrated with primary care, there are considerably higher rates of consultation. The same is true in community mental health centres, where the increase in workload is mainly accounted for by people with psychosocial and minor mental disorders. Patients with long-term or unresolving symptoms require referral to ‘out-patient’ specialist services which can be based either in a hospital setting or in the community (Conway et al. 1994a). Patients prefer specialist contacts to be made close to general practice rather than at out-patients, with health centres being the most acceptable venue (Wing 1994).

E36. Conway and colleagues (1994a) reviewed the literature on hospital closure. They identified an earlier review (O’Driscoll 1993) which did not find any long-term prospective studies of the effects of hospital closure. The reviewed studies point towards the overall reduction in bed numbers, the changing profile of hospital in-patients, the emergence of the ‘new long-stay’ population, and the high levels of dependency in the residual ‘old long-stay’ patients. Further, in studies of patients discharged from in-patient care to the community, the use of after-care was associated with being able to remain in the community, and patients experienced better outcomes through foster and nursing home placements than continued hospitalisation. However, these benefits were reliant upon adequately staffed community facilities. The authors conclude that ‘patients discharged from long-stay mental hospitals need:

- facilities for acute relapses
- rehabilitation for continuing social and behavioural problems
- a number of highly supported residential places for those who prove difficult to place’.

E37. Community-based care has been shown to be as, or more effective compared with traditional hospital-based in-patient and out-patient care. However, this result is specific to short-term follow-up and based on populations where certain groups of patients such as drug or alcohol users were excluded (Consumers’ Association 1994). Conway and colleagues (1994a) examined RCTs of the effectiveness of community-based treatment in comparison with
hospital-based psychiatric care. From this they raise a number of issues related to the provision of community care:

- It can be provided at comparable cost to standard hospital care for some seriously ill psychiatric patients.
- Social and clinical outcomes are as good as and possibly better than those in standard hospital care.
- Hospital bed use is reduced but not eliminated.
- It is preferred by both patients and relatives and results in higher patient self esteem than hospital care.

**E38.** Non-experimental evaluations of community-based services do not always show the beneficial outcomes identified in the RCTs. Although a number of studies have shown improvements in levels of social functioning, rates of hospitalisation and length of stay, other studies have found less favourable outcomes. Conway and colleagues (1994a) conclude that services are more likely to be successful if clear objectives are defined and services are targeted appropriately. A complete range of services is required to evaluate fully outcomes in community programmes. All individual service components must be fully integrated within the programme of care. Social interventions, as well as mental health services, may be crucial in improving social functioning for the seriously mentally ill. A survey of targeting community mental health services to people with schizophrenia with high levels of psychotic symptoms and social disability found that although psychiatric symptoms were considerably reduced, there was no significant change in social disability (Conway et al. 1994b).

**E39.** The Health of the Nation handbook for mental illness (Department of Health 1993b) provides references and brief descriptions of ten primary studies which, it is stated, lend broad support to the idea that there are benefits of locally focused comprehensive community services.

**E40.** Conway and colleagues (1994a) have examined evaluations of separate components of community care including day services, community mental health centres, crisis intervention and residential care. Most studies identify beneficial aspects of the component under evaluation and highlight key areas, but these are not always readily translatable into everyday practice because of the reliance on other aspects of care. For example, day hospitals can prevent up to 40% of potential acute admissions, but without active long-term aftercare an additional 20% of potential admissions will fail to utilise the service. Similarly, 24 hour crisis intervention can reduce the need for hospital admission, but better results are achieved with high staff to patient ratios and access to residential crisis beds.
E41. Conway and colleagues (1994a) have examined the evidence relating to psychiatric rehabilitation. The aim of psychiatric rehabilitation is to help patients achieve and maintain their best functional outcome. This is done by individual assessment and treatment in a number of different dimensions, and requires on-going monitoring, support and therapy. The authors identify an earlier review (Dion and Anthony 1987) which concludes that rehabilitation is associated with positive outcomes in a number of areas, including hospital readmission rates, community tenure, employment, satisfaction and costs.

E42. Case management is a formal mechanism for organising service components into an integrated system of care. Thus, it is only as good as the sum of the individual service inputs and could potentially be worse if not properly co-ordinated. Conway and colleagues (1994a) have reviewed the evidence relating to case management in studies which look at the process of case management rather than the components of the services being co-ordinated. The authors conclude that ‘the organisational structure of services may heavily influence whether care provision meets its stated goals’.

E43. Holloway et al. (1995) reviewed the outcome literature for case management to evaluate its effectiveness for caring for the mentally ill in the community. They find a wide and diverse range of definitions and descriptions in the literature making comparison difficult. Case management is found to be more effective than traditional services in terms of hospitalisation rates, but there is little attempt to identify which components of case management are effective. The majority of studies included in the review are from the US, and so the generalisability of the conclusions is questionable. An RCT evaluating social services case-management for long-term mental disorders found no significant differences between groups at 14 months in terms of a number of measures including: needs, quality of life, employment status, severity of psychiatric symptoms (Marshall et al. 1995). The Schizophrenia Cochrane Collaborative Review Group is about to publish a systematic review on case management. The aim of this review is to determine the effectiveness of three different forms of case management: high intensity as an alternative to hospital treatment; intensive as a treatment for patients in the community; and low intensity as a treatment for patients in the community.

E44. Conway and colleagues (1994a) highlighted the need for effective multi-disciplinary team working to implement successful programmes of care. Failure in the provision of service is often associated with a lack of clearly defined goals, or failure to change models of staff working, leading to high levels of staff turnover and ‘burnout’. As they state ‘Comprehensive care will involve a range of different professionals and services; co-ordinated care requires a degree of co-operation, flexibility and shared aims; and continuity of care requires that high quality cover be provided in the case of staff absences’.
Further they identify five key stages in successful multi-disciplinary team work:

- clarify goals and procedures
- develop leadership skills
- clarify roles
- address responsibility and accountability
- look after the team.

E45. The Government has produced guidance for the arrangements for inter-agency working to implement the Care Programme Approach (CPA) for the care outside hospital of people who are mentally ill (Department of Health 1995). The aim of the approach is to provide treatment which is individually tailored to the needs of the patient, integrated across all the required services and flexible enough to deal with changes over time. There are four main elements to the CPA:

- systematic arrangements for assessing the health and social needs of people accepted by the specialist psychiatric services
- the formulation of a care plan which addresses the identified health and social care needs
- the appointment of a key worker to keep in close touch with the patient and monitor care
- regular review, and if need be, agreed changes to the care plan’.

Such an approach needs to be evaluated to ensure it is being implemented in full. For example, a preliminary analysis of 25 community care plans produced by local authorities in England, revealed variation in the content and formats of the plans (Hardy et al. 1993).

Costs

E46. Historically, there has been little economic evaluation of mental health care in the United Kingdom. Only seven evaluations were identified in a review of the literature, some of which were methodologically flawed (O’Donnell et al. 1988). There have been economic evaluations subsequently. For example Knapp et al. (1994) found a programme of home-based care for people with severe mental illness was cost-effective compared to emergency hospital admission. Although there is evidence to suggest that community-based services are cost-effective it is not clear what the total cost will be of shifting to community care. Economies of scale in providing care in large institutions will not be exploited, as there are reductions in psychiatric beds and more community care. As care is moved into the community, responsibility for funding may fall on different services and authorities. Hallam et al. (1994) evaluated the costs of accommodation and care of community provision for former long-stay psychiatric hospital patients. They found that district health authorities were funding half of the costs of supporting the hospital leavers in...
the community. The remaining funding burden was borne by a range of agencies, which resulted in pressure on staff case-loads and budgets.

Conclusions

E47. There is not a large amount of good quality evidence on the setting and delivery of mental health services. Further there are a number of methodological issues which need to be borne in mind when interpreting the results of trials. As has been noted in a number of the reviews (Conway et al. 1994a; Effective Health Care 1993), it is often difficult to replicate the results of trials into everyday practice. This may be due to any number of reasons, for example it may be difficult to generalise to the wider population of people with severe mental illness, from the results of RCTs based on patients recruited to trials with very strict inclusion criteria. Also, variations in the availability of other support services as well as cultural, socio-economic and geographic variations may influence study findings. Notwithstanding these caveats, there is some evidence that community care is effective and cost-effective compared with hospital provision.

E48. Conway and colleagues (1994a) conclude that ‘people with severe and chronic psychiatric illness can be cared for predominantly in the community, with similar or superior outcomes to a hospital-based model of care’ and that the ‘best outcomes appear to be achieved when services are set up with deliberate aims’. However, ‘a community focused service will not be achieved at a reduced cost’.

E49. The Mental Health Foundation (1994) published an enquiry into community care for adults with severe mental illness. On the subject of organising health and social care the report concludes ‘The right services must be delivered in the right way. There is confusion about the responsibilities of health and local authorities, and there are deficiencies in health and social care. Systems must be simplified and clear lines of accountability established’.

E50. The implications of this work for the outcomes project are mixed. It may well be desirable to use the organisation of services as a proxy measure for quality of care when assessing outcomes. However, there is no clear evidence to precisely identify particular organisational methods which could be used for such an indicator.
Candidate outcome indicators were identified by the Group with the help of the following:

- the health outcome model for severe mental illness (see Section 2)
- various classifications of the characteristics of outcome indicators.

The Group noted that indicators may be related to:

i. environmental factors in the general population or relating to the individual
ii. knowledge, attitudes and behaviour in the general population
iii. knowledge, attitudes and behaviour of individuals with severe mental illness
iv. individuals' symptoms, function, health status and well-being
v. individuals' clinical state
vi. individuals' pathological and physiological state
vii. events occurring to individuals as the endpoints of the earlier occurrence of disease and/or interventions such as contacts with general practitioners, psychiatric nurses or social workers, issuing of prescriptions, out-patient visits, in-patient admissions and death
viii. knowledge, satisfaction with service delivery and emotional and physical well-being of carers.

The data sources for the indicator entities noted in paragraph F2 will differ. It is likely that:

- indicators for (i) and (ii) would come from population surveys
- indicators for (iii), (iv) and (viii) would come from service users and carers either opportunistically or when specifically called
- indicators for (v) and (vi) would come from doctors and other professionals
- indicators for (vii) would come from routine information systems.

The Group recognised the high cost and complexity of obtaining information from continuous data collection systems. Particular consideration was given to obtaining outcome indicator data from sample survey techniques when it is not essential to have continuously collected information.

Four characteristics of an outcome indicator have been identified and each has been classified. They are:

- measurement perspective, relating to whose perspective the indicator is most relevant (see paragraph F6)
- specificity (see paragraph F7)
- measurement timeframe (see paragraph F8)
- outcome relationship, in that the indicator is either a direct or an indirect, proxy measurement of outcome (see paragraph F9).
F6. For the Group's purposes, measurement perspective was classified as that from the service user's, the carer's, the clinical or population's viewpoint. In the treatment of severe mental illness ability to work may be most relevant to the service user's perspective, while clinical concerns may properly focus on the taking of medication. The population perspective has a broader view, best addressed by measures able to assess the impact of the condition as a whole. Of course, these perspectives are not necessarily in opposition and will often be associated with shared goals. Where possible, a set of indicators should be developed which satisfies all three measurement perspectives.

F7. The specificity of an indicator relates to whether it is specific or generic in application. For example, the measurement of peak expiratory flow rate is specific to lung function and fairly specific to chest disease. The measurement of blood pressure is much less specific and would be influenced by a number of conditions. Condition-specific indicators have the advantage that their relative insensitivity to other conditions is likely to increase their sensitivity to changes in the condition of interest. Generic measures provide outcomes relevant to a wide range of conditions. A comprehensive indicator set might contain examples of both generic and specific indicators.

F8. The measurement timeframe relates to whether the indicator is:

- cross-sectional and thus an indicator at a single point in time for any one individual
- a longitudinal measure of progression over time for any one individual.

F9. The Group's main task has been to develop direct indicators of health outcome although in some areas it has been difficult to identify or obtain such information. However, it is recognised that some care processes are so closely related to the production of benefits that the successful completion of the intervention can be used as a proxy measure of the actual outcome. In the absence of direct outcomes, proxy indicators have therefore been developed.

F10. There is increasing recognition of the importance of outcome measures derived from data generated by service users and carers. For the purposes of our work, three main areas of interest relating to service users and carers have been identified:

- impact of the condition
- satisfaction with the care provided and the outcomes achieved
- awareness of the management of the condition and the assistance available.
**F11.** The condition may impact on the service user in terms of:

- physical and psychological health
- specific impairments associated with the condition
- disabilities
- handicaps.

**F12.** The condition may impact on carers in terms of their:

- physical and physiological health
- social functioning.

**F13.** With the assistance of the check-lists and a knowledge of the disease supplemented by commissioned work, the Group addressed the following key questions:

- What are professionals trying to achieve for each service user?
- What can each service user realistically expect will be achieved for him/herself?
- What should be achieved for the population as a whole in respect of the prevention, care or cure of severe mental illness?
APPENDIX G: GUIDANCE NOTES FOR CANDIDATE INDICATOR SPECIFICATIONS

**Indicator title**  
A short title to identify the indicator.

**Intervention aim**  
Distinguishes the level of intervention for which the indicator is primarily developed. For a given condition, an ideal set of indicators should be reasonably balanced across the spectrum of health intervention types. For severe mental illness these stages are:

- reduce or avoid risk of severe mental illness
- detect severe mental illness early
- maintain function and reduce need for hospital admission
- restore function and reduce risk of relapse following hospital admission
- promote independent living and well-being
- sustain a collaborative approach between service providers, service users and their carers
- support carers and reduce the impact of severe mental illness on them
- ensure protection and good physical health of service users
- ensure protection of carers, service providers and the public.

**Characteristics**  
Classifies the indicator on four dimensions:

- Specificity: *condition specific* or *generic*.
- Perspective: *population, clinical, service user* or *carer*.
- Timeframe: *cross-sectional* measure or *longitudinal* assessment of change.
- Outcome relationship: whether it is a *direct* measure of outcome or an *indirect* measure of structure or process, used as a proxy for outcome.

**Indicator definition**  
In addition to a definition of the variable of interest, the description specifies:

- how the variable is to be aggregated across cases, e.g. definitions of both a numerator and a denominator
- if a variable is to be reported with respect to a set of denominators e.g. mortality broken down by age and sex
- if appropriate, how longitudinal change in the variable is to be represented, e.g. over what time interval and whether absolute difference or proportional change.

**Rationale**  
A brief statement of the reasons and objectives behind the indicator, both in terms of the issues it addresses and its selection from a range of potential alternatives.
Severe Mental Illness Outcome Indicators

Definition of severe mental illness

As a result of the study and further discussion by the Group the definition of severe mental illness, which only includes a service provider perspective, is as follows:

- There must be a mental disorder as designated by a mental health professional (psychiatrist, mental health nurse, clinical psychologist, occupational therapist or mental health social worker) AND EITHER

- There must have been a score of 4 (severe/very severe problem) on at least one, or a score of 3 (moderately severe problem) on at least two, of the HoNOS items 1-10 (excluding item 5 ‘physical illness or disability problems’) during the previous six months OR

- There must have been a significant level of service usage over the past five years as shown by:
  - a total of six months in a psychiatric ward or day hospital, or
  - three admissions to hospital or day hospital, or
  - six months of psychiatric community care involving more than one worker or the perceived need for such care if unavailable or refused.

Potential uses

The following classification has been used:

- care and treatment of individual service users
- local management of practice
- local clinical audit
- provider based comparisons
- population based comparisons
- assessment of regional/national trends or progress towards targets.

It is recognised that a given indicator may serve several purposes. Indicators that are valuable for treatment and care are likely to have practical advantages with respect to data collection in a clinical setting. However, in order for such indicators to be useful for other purposes, a method of aggregation across cases must be specified for the variable of interest.

Potential users

The following classification has been used:

- national/regional policy makers
- provider management
- commissioners
- clinicians
- consumers/public.
Possible confounders

This section has attempted to identify the population risk factors likely to influence the outcome indicator, and therefore useful in its interpretation. Where such factors are well defined and have a clear or potential association with the outcome of interest, they may be used to specify denominators to be included in the indicator definition itself.

Data sources

Where possible, existing sources of data have been identified for deriving the indicator and the degree to which complete coverage of the population of interest would be obtained has been noted. Where data are not widely available from existing systems, suggestions for new methods of data collection, capable of wide implementation have been made.

Data quality

While the theoretical capabilities of existing and proposed information systems are outlined above, the actual or expected limitations of those systems - in terms of their completeness and accuracy etc. - are noted in this section.

Comments

General comments regarding the indicator's definition, validity, practicality etc.

Further work required

Suggestions about the additional research and development work required to complete the indicator's specification to a level appropriate for large scale piloting.

Conclusions & priority

A statement indicating the working group's assessment of the priority for implementation.

References

Appropriate references used in the construction of the indicators.
SCOPE

H1. The Working Group commissioned two literature reviews related to outcome measures for people with severe mental illness:

- overview of outcome measures
- impact on carers.

OVERVIEW OF OUTCOME MEASURES

Introduction

H2. Measuring tools cannot be selected before key decisions have been made to identify WHAT we want to measure - the desired outcomes - and WHY we want to measure them. HOW they are measured can then be decided by matching desired outcomes with existing instruments to identify how well they are captured. Identifying the desired outcomes of severe mental illness involves consideration of:

- how severe mental illness is defined
- stage of the illness
- care setting
- whose perspective is to be explored.

H3. Attention to these issues will also help to clarify:

- use to which outcomes data will be put
- level at which outcomes data will be aggregated.

Identifying the desired outcomes

H4. In identifying desired outcomes the following issues must be addressed:

- definition of severe mental illness
- stages of the illness
- care settings
- whose perspective
- uses of outcome information
- aggregation of data.

H5. The use of the term severe mental illness to classify patients and the sort of definition to be adopted in this classification has implications for the types of desired outcomes and the way in which they are defined and measured. These issues are discussed in Appendix C.
H6. Many different disorders might be described as severe mental illness, each with a different natural history. At different points in the individual’s illness career, different outcomes may be relevant (Godfrey and Townsend 1995). It may not be possible for any single measuring tool to capture all the relevant desired outcomes at different stages of the illness.

H7. The care of people who are severely mentally ill takes place in a wide variety of settings spanning primary, secondary and community care and includes NHS, social services, voluntary and private sector agencies. This variety of settings has practical implications for the collection of outcomes information. It may be impossible or impractical to apply the same measuring tools to this wide range of care settings.

H8. Multiple key actors are involved in the purchase and provision of care for people who are severely mentally ill, each with their own perspective on the desired outcomes. Although there will be some similarities in the types of desired outcomes between key actors, there will be important differences in the way these outcomes are defined and prioritised. It is necessary to consider whether the measuring tools selected provide a balanced view of all these different perspectives.

H9. The potential use of outcomes information has important implications for the way in which the outcomes are measured and thus the measuring tools selected. Exhibit H1 shows the key actors involved in severe mental illness with examples of their desired outcomes and the way in which they might use the outcome measure information. Can the same measuring tool be useful to professionals in providing care and at the same time be used by commissioners to monitor the effectiveness of services for people who are severely mentally ill?

H10. Two issues relate to the level at which the data will be aggregated. The first is the reporting of outcomes information; while professionals may wish to know the progress of service users in several domains, managers and commissioners may only require a composite indication of health. Thus it is necessary to consider whether the measuring tools can provide clinically useful cut off points and whether the data produced can be aggregated in a meaningful way. The second relates to the presentation of the data; is the outcomes information presented in terms of individual patients, as an average of a number of service users or in terms of population rates. The precision required of a measuring tool in order to make valid inferences will vary depending on how the data are presented.
### EXHIBIT H1: THE KEY ACTORS, EXAMPLES OF THEIR DESIRED OUTCOMES AND USES OF OUTCOME INFORMATION

<table>
<thead>
<tr>
<th>Broad group</th>
<th>Key players</th>
<th>Examples of desired outcomes</th>
<th>Uses of outcomes information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Users</strong></td>
<td>People with SMI</td>
<td>Get back to my old self again Be able to live at home Avoid unwanted drug side effects Feel respected by health professionals Be involved in treatment decisions Access to respite care when required</td>
<td>Monitor own progress Inform clinician of progress Decide which service to attend</td>
</tr>
<tr>
<td><strong>Carers</strong></td>
<td>Carers of people with SMI eg relatives, friends or others</td>
<td>Improve relations with family/friends Maintain adherence to medication Access to a crisis line or support Access for person with SMI to respite care</td>
<td>Monitor progress Inform clinician of progress Advice on which service to attend</td>
</tr>
<tr>
<td><strong>Medical</strong></td>
<td>Psychiatrists</td>
<td>Reduce specific clinical symptoms Improve interpersonal and social functioning Reduce risk of suicide and self harm Maintain adherence to medication</td>
<td>Assess needs of patient Plan treatment programme Monitor progress of patient Monitor own performance</td>
</tr>
<tr>
<td><strong>Other health/social services professionals</strong></td>
<td>Clinical psychologists Occupational therapists Community psychiatric nurses Social workers General practitioners</td>
<td>Improve patient well-being Reduce psychological symptoms Improve interpersonal, social and vocational functioning Provide support to carers Reduce risk of suicide and self harm</td>
<td>Assess needs of patient Plan treatment programme Monitor performance of patient Monitor own performance</td>
</tr>
<tr>
<td><strong>Management</strong></td>
<td>Community trust Social services</td>
<td>Reduce risk of suicide Reduce re-admission rates Maintain information systems Key worker identified Patient assessed and care plan reviewed regularly Reduction of loss to follow-up Improve patient satisfaction</td>
<td>Monitor load on services Measure overall quality and effectiveness of the service Resource management Support clinical audit activities Assess the achievement of local targets</td>
</tr>
<tr>
<td><strong>Commissioning/policy makers</strong></td>
<td>Health authorities GP groups NHS Executive</td>
<td>Reduce prevalence of illness Reduce suicide rates Reduce re-admission rates Reduce levels of violence in community Implementation of CPA &amp; supervision registers Joint working between NHS and social services</td>
<td>Assess the needs of the population Monitor load on services Measure the effectiveness of services Assess the achievement of national targets Policy development</td>
</tr>
<tr>
<td><strong>Voluntary organisations</strong></td>
<td>MIND National Schizophrenia Fellowship</td>
<td>Empower patients Provide information to patients Patient advocacy</td>
<td>Lobbying Service planning Policy development</td>
</tr>
<tr>
<td><strong>Other statutory organisations</strong></td>
<td>Local authority Criminal justice system</td>
<td>Reduce number of homeless people Protect the patient Protect the public</td>
<td>Policy development Priorities for sentencing</td>
</tr>
</tbody>
</table>

SMI is used in the Exhibit as an abbreviation for Severe Mental Illness.
Measuring the desired outcomes

**H11.** A number of common broad topics identified in the grid formed the basis of this review of outcome measures relevant to people with severe mental illness:

- service users’ symptoms
- psychosocial outcomes
- adverse events
- structure and process.

**H12.** For each topic consideration has been given to:

- Domain coverage, in terms of whether the measuring tools:
  - capture a wide range of desired outcomes
  - incorporate a range of perspectives
  - cover all key stages of the condition?

- Practicality, in terms of whether measuring tools:
  - are appropriate for routine practice
  - can be administered within a feasible timescale
  - require training in their administration and interpretation?

**Symptoms**

**H13.** There is a multitude of interview, self-rated and clinician-rated measures for the assessment of psychiatric symptoms. They generally assess the following classifications of symptoms with their effects on the individual’s functioning:

- cognitive - e.g. obsessive thoughts
- behavioural - e.g. self harm and suicidal behaviour
- mood/affective - e.g. depression, anxiety
- biological/somatic - e.g. gastrointestinal, sleep.

**H14.** The instruments vary considerably in their scope and specificity. For example, some instruments are designed to assess specific disorders while others cover a broader range of psychopathological symptoms. Interviews and clinician rated questionnaires generally only cover clinically defined desired outcomes. Self rated questionnaires attempt to translate symptoms into lay language although there is some dispute regarding the validity of an individual’s assessment of symptoms (Bech 1993).
H15. The practicality of the instruments can be inferred from their current uses within psychiatric practice and research which are as follows (Hamilton 1976):

- to detect the presence of psychiatric illness or to make a specific diagnosis of psychiatric illness
- to assess the severity of diagnosed psychiatric disorders
- to select an appropriate treatment
- to predict prognosis.

H16. The majority of the instruments have been designed within research settings and are often too lengthy for use in routine practice. A substantial percentage require trained interviewers to administer the interview schedules. There is little evidence of their application to routine data collection in order to monitor the effectiveness of services. Any choice of these instruments is certain to involve a compromise and none are likely to meet all the practical or psychometric criteria. Andrews et al. (1994) found none to be adequate on all their criteria.

Psychosocial outcomes

H17. The measurement of psychosocial outcomes is a large and extremely ill defined area. The distinction between symptoms and psychosocial health in individuals with severe mental illness is even less clear cut than for physical illness and many of the measures reflect this. The kinds of measures that are subsumed under this topic are:

- quality of life measures
- health related quality of life measures
- social, psychological and instrumental functioning measures
- life satisfaction measures and patient satisfaction measures.

There is a great deal of overlap between the topics and domains covered by these measures.

H18. The kinds of topics they cover are:

- daily activities
- interpersonal and family relationships and social support
- self esteem/self confidence
- economic/employment concerns and housing/accommodation concerns
- general health status and psychological well being
- satisfaction and coping
- psychiatric symptoms.
H19. Although there is a great deal of overlap between the kinds of topics covered within the questionnaires, there are large differences in the conceptualisation and measurement of quality of life, functioning and patient satisfaction. No universally accepted operational definition of quality of life has been formulated and one might question the usefulness of the term ‘quality of life’.

H20. Some measures assess distinct domains only, such as social support, while others assess a range of domains thought to contribute to a person’s quality of life or functioning. Given a lack of universal definitions, it is questionable whether there is adequate coverage of the domains in order to provide a valid reflection of a person’s satisfaction, quality of life or functioning.

H21. Patient satisfaction measures often do not adequately represent the factors that patients consider to be important (Glass 1995; Hansson et al. 1993). Although ‘quality of life’ and functioning measures address issues of importance to people, the way in which the questions are structured rarely reflects the individual’s conceptualisation of their functioning or quality of life, but are based on clinical impressions.

H22. As with symptoms, the majority of the measuring tools to assess the psychosocial outcomes of severe mental illness have been developed for research settings and as such, the majority are too long for routine practice. The measures vary in the amount of training required to administer and score the measure.

H23. Given the problems of definitions and topic specification it is important to identify the topic areas most relevant to the functioning and/or quality of life of patients defined as severely mentally ill and then assess how well these are covered by the measures in existence. It is necessary to consider whether the same topics are relevant to all patients with different disorders, or whether assessment should be restricted to those issues common to all disorders within any definition of severe mental illness.

H24. Andrews et al. (1994) assessed 20 functioning, 17 quality of life, eight patient satisfaction and 27 multidimensional measures (see Exhibit H2). They found no quality of life or patient satisfaction measures adequately met all their criteria but recommended one functioning questionnaire and five multidimensional measures for further field testing:

- The Role Functioning Scale (RFS).
- Behaviour and Symptom Identification Scale (BASIS).
- Health of the Nation Outcome Scales (HoNOS).
- Medical Outcomes Study Short Form (SF-36).
- Mental Health Inventory (MHI).
- Life Skills Profile (LSP).
### EXHIBIT H2: OUTCOME MEASURES REVIEWED BY ANDREWS ET AL. (1994).

<table>
<thead>
<tr>
<th><strong>Symptom measures</strong></th>
<th><strong>Functioning measures</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Beck Anxiety Inventory</td>
<td>Brief Disability Questionnaire</td>
</tr>
<tr>
<td>Beck Depression Inventory</td>
<td>Classification of Intellectual and Other Psychological Impairments</td>
</tr>
<tr>
<td>Brief Psychiatric Rating Scale</td>
<td>Client Adjustment Rating Scales</td>
</tr>
<tr>
<td>Brief Psychiatric Rating Scale (Expanded)</td>
<td>Community Disability Scale</td>
</tr>
<tr>
<td>Brief Psychiatric Rating Scale (Nursing Modification)</td>
<td>Functional Status Questionnaire</td>
</tr>
<tr>
<td>General Health Questionnaire</td>
<td>Global Assessment Scale</td>
</tr>
<tr>
<td>Hamilton Anxiety Rating Scale</td>
<td>Goal Attainment Scale</td>
</tr>
<tr>
<td>Hamilton Depression Rating Scale</td>
<td>Goal Attainment Scale for Psychiatric Inpatients</td>
</tr>
<tr>
<td>Manchester Scale</td>
<td>Groningen Social Disabilities Schedule</td>
</tr>
<tr>
<td>Montgomery-Asberg Depression Rating Scale</td>
<td>Independent Living Skills Survey</td>
</tr>
<tr>
<td>Present State Examination</td>
<td>MRC Social Role Performance Schedule</td>
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<tr>
<td>Royal Park Multidiagnostic Instrument for Psychosis</td>
<td>Rehabilitation Evaluation Hall and Baker</td>
</tr>
<tr>
<td>Scale for the Assessment of Negative Symptoms</td>
<td>Resource Associated Functional Level Scale</td>
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<tr>
<td>Scale for the Assessment of Positive Symptoms</td>
<td>Role Functioning Scale</td>
</tr>
<tr>
<td>State Trait Anxiety Inventory</td>
<td>Social Adjustment Scale</td>
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<tr>
<td>Symptom Checklist 90</td>
<td>Social Adjustment Scale for Schizophrenics</td>
</tr>
<tr>
<td>WHO Psychological Impairments Rating Schedule</td>
<td>Social Adjustment Scale Self Report</td>
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<tr>
<td>Zung Self Rating Depression Scale</td>
<td>Social Behaviour Schedule</td>
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<td></td>
<td>Social Functioning Scale</td>
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<tr>
<td></td>
<td>Structured and Scaled Interview to Assess Maladjustment</td>
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<td></td>
<td>WHO Psychiatric Disability Schedule</td>
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</tbody>
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<table>
<thead>
<tr>
<th><strong>“Quality of life” measures</strong></th>
<th><strong>Multidimensional measures</strong></th>
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<tbody>
<tr>
<td>Brief Follow up Rating</td>
<td><strong>Behaviour and Symptom Identification Scale</strong></td>
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<tr>
<td>Community Adjustment Form</td>
<td>Current and Past Psychopathology Scales</td>
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<tr>
<td>Comprehensive Quality of Life Scale for Adults</td>
<td>Denver Community Mental Health Questionnaire</td>
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<tr>
<td>General Well Index</td>
<td>Duke-UNC Health Profile</td>
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<td>Lancashire Quality of Life Profile</td>
<td>Duke Health Profile</td>
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<tr>
<td>Oregon Quality of Life Questionnaire</td>
<td><strong>Health of the Nation Outcome Scales</strong></td>
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<td>Quality of Life Checklist</td>
<td>Katz Adjustment Scales</td>
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<tr>
<td>Quality of Life Enjoyment and Satisfaction Questionnaire</td>
<td>Lehman Quality of Life Interview</td>
</tr>
<tr>
<td>Quality of Life in Depression Scale</td>
<td>Levels of Functioning Scale</td>
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<tr>
<td>Quality of Life Index</td>
<td><strong>Life Skills Profile</strong></td>
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<tr>
<td>Quality of Life Questionnaire</td>
<td>Major Problem Rating System</td>
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<tr>
<td>Quality of Life Scale</td>
<td>McMaster Health Index Questionnaire</td>
</tr>
<tr>
<td>Satisfaction with Life Domains Scale</td>
<td><strong>Medical Outcomes Short Form 36</strong></td>
</tr>
<tr>
<td>Single Item Indicators of Well Being</td>
<td><strong>Mental Health Inventory</strong></td>
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<tr>
<td>Social Dysfunction Rating Scale</td>
<td>Morningside Rehabilitation Status Schedule</td>
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<tr>
<td>Subjective Well Being Inventory</td>
<td>MRC Needs for Care Assessment</td>
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<tr>
<td>WHO Quality of Life Assessment</td>
<td>Nottingham Health Profile</td>
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<td></td>
<td>Psychiatric Evaluation Form</td>
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<td></td>
<td>Quality of Life Index for Mental Health</td>
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<td></td>
<td>Quality of Well Being Scale</td>
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<td></td>
<td>Rating of Social Disability</td>
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<td>Resource Associated Functional Level</td>
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<td>Sickness Impact Profile</td>
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<td>Social Behaviour Assessment Schedule</td>
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<td>Social Functioning Schedule</td>
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<td></td>
<td>Social Maladjustment Schedule</td>
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<tr>
<td></td>
<td>Vermont Community Questionnaire</td>
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</tbody>
</table>

Tools highlighted in **bold** denote those recommended by Andrews et al. (1994)
Adverse events

H25. Adverse events refer to a wide range of undesirable outcomes such as suicide, harm to self and others, the side effects of drugs and a relapse of symptoms. An important question is whose perspective is used to define the event as adverse as there may be differences in opinion between, for example, service users and clinicians with regard to the side effects of drugs and compliance with medication and even suicide (Rogers et al. 1993).

Structure and process

H26. Good process and structure may be valuable ends in their own right and are conducive to good outcomes for service users. The distinction between structure, process and outcomes is not clear cut and depends very much on where the ‘end point’ line is drawn. Often process and structure measures are used as proxies for outcomes. The kinds of process and structure indicators relevant to severe mental illness could reflect the recommendations set out in the Health of the Nation key area handbook for mental illness (Department of Health 1993b) or reflect the implementation of the Care Programme Approach (Department of Health 1992) which are assumed to lead to good patient outcomes. These might include:

- implementation of CPA
- development of joint purchasing between NHS and social services
- multidisciplinary community health teams
- screening and health promotion programmes in general practice
- information systems.

H27. Although some information on structure and process is available routinely, much of the data does not reflect the changing arrangements for the purchase and provision of care for people who are severely mentally ill. Thus it may be difficult to develop indicators for many of the processes and structures mentioned above. However, the DoH together with the Information Management Group and the Royal College of Psychiatrists Research Unit have proposed a new minimum patient data set for mental health care which should overcome many of the existing gaps in patient information.
IMPACT ON CARERS

Introduction

H28. The role of informal carers of people with severe mental illness is poorly recognised and rarely acknowledged. At present there is no framework to assess the outcomes of caring for carers in a way that is sensitive, systematic and effective. Most importantly there is no framework in place to do anything with the information if and when it is obtained.

H29. The aims of this Section are to:

- explore the nature of caring and carers
- summarise the literature on the impact on carers of caring for someone with a long-term illness
- suggest areas of carer outcome for closer consideration
- outline available outcome measures for assessing the impact of caring
- suggest a range of possible outcome indicators for the carers of people with severe mental illness.

What is a carer?

H30. There are several definitions of a carer:

- ‘Anyone who looks after or cares for a handicapped person to any extent in their own home or elsewhere’ (Equal Opportunities Commission 1982).
- ‘A person looking after or providing some form of regular service for a sick, handicapped or elderly person living in their own or another household’ (Green 1988).

H31. Both the quoted definitions belie the complexity of caring. In their valuable paper Nolan et al. (1995) outline multiple definitions and models for the meaning of caring. These try to separate out the different components of caring such as issues of support, help, protection, social dynamics, the complex emotional/affective components and the physical and behavioural aspects (Quereshi 1986; Pearlin et al. 1990). What emerges is that caring comprises all of these dimensions as well as the practical day-to-day care giving. Attention in any measurement process should not be given solely to the physical aspects of caring at the expense of these other aspects.
Bowers (1987) has proposed that caring should be purpose orientated rather than task orientated and suggested that there are five types of care:

- anticipatory care, based on anticipated future need
- preventive care, monitoring at a distance
- supervisory care, direct help with activities
- instrumental care, doing activities for the cared for
- protective care, maintaining the self esteem of the cared for person by minimising their awareness of failing abilities and maximising the extent to which they perceive themselves independent.

Nolan et al. (1995) add three further types:

- preservative care, preserving the cared for persons sense of ‘self’
- (re) constructive care, developing new and valued roles
- reciprocal care, receiving help from the cared for at the financial, material and psychological levels and including the satisfaction of caring.

Much of a carer’s role is invisible, which has implications for the latent needs and outcomes of carers. Anticipatory and preventive care do not involve direct help and as such may not come to the attention of the health and social services; however both have a considerable effect on the carer’s life. Recent research on carer stress (Nolan et al. 1994) has shown that physical caring tasks are poor predictors of carer stress, and that relationship and social issues are more important. Instrumental and supervisory care are also perceived by carers as the least stressful aspects of caring with protective care being most stressful. Any examination of the carer’s perspective on outcome must therefore, recognise the different types of caring role, its (in)visibility and associated impact on the carers.

The manner in which someone becomes a carer is of importance and depends on the type of illness the patient suffers. Some carers, for example those caring for the terminally ill, become carers slowly while others, as in the case of stroke, may become carers overnight with no time for preparation. With the tendency to early discharge or home care a carer may have little or no time to prepare for their new role. They may have little understanding or knowledge of the illness and their ability to assimilate information at a time of crisis is likely to be diminished. Both the ability and willingness of a carer to care is important to establish at an early stage. Carers may have to make important decisions while learning new skills and must be supported both psychologically and practically. It has been noted that professional consultation with carers is very often lacking and that the carers often lack knowledge about both the illness and services available (Norman 1987).
H36. Carers need (sufficient) information about the illness, progress and prognosis, together with information about appropriate services and voluntary agencies. They may also need practical skills training. For example, the carer of a person who is mentally ill may need instruction about medication. As Nolan et al. (1994) point out, establishing the ground rules from the outset should be seen as an investment in the future and adopted as minimal good practice. It must be remembered that carers needs are ongoing and continually evolving, hence their information and skill requirement must be reviewed. Whilst the emphasis of community care is on sustaining carers rather than relieving them of the caring role (Silvey 1991) carers have a right not to care if they so wish.

The impact of caring

H37. When considering the impact of caring for carers it is essential that all the aspects of caring are considered and that a wide definition of carer is assumed. Since caring has physical, psychological, social and economic aspects, the consequences of caring must be considered in these terms. Although the majority of work on the impact and consequence of caring on the carer has focused on negative outcomes it must be remembered that there are also positive, rewarding and satisfying outcomes to caring.

H38. There has been much work on carer burden and stress. Carer burden refers to the load or responsibilities carried, or to the time and effort required for one person to attend to the needs of another (Montgomery et al. 1985). Much of the research has taken place in the context of psychiatric illness, with increasing interest in recent years in those caring for people with physical disabilities.

H39. Burden can be thought of as encompassing the health related status and behaviour of the patient, the tasks required of the carer and the impact of these tasks on the carer's life (Poulshock et al. 1984). Carer burden can be divided into objective (external) burden and subjective (as experienced by the carer) burden. Additionally burden can be directly attributable to the patient or to other sources. Increasing burden may affect the carer's subjective well being leading to 'stress'. Precipitating factors (Nolan 1994) include:

- carers feeling out of control of events
- caring for a person who is unappreciative, demanding and manipulative
- not receiving sufficient support from the family and lack of adequate finances.
H40. Although burden and stress are useful concepts they rely on a simple cause and effect model suggesting that exposure to certain situations caused stress. Individuals react to events in different ways; all events are not necessarily stressful all of the time and not all events are equally stress provoking to all people. Stress and burden are multidimensional concepts with social, psychological, physical and economic components. It may be valuable to consider these separately.

H41. The literature, which has been reviewed, highlights a number of areas of relevance in considering the outcomes for carers:

- information and skills (see paragraph H42)
- depression, anxiety and stress which can be features of caring and may have a considerable impact on the carer
- satisfaction with care and with caring as there is growing evidence that satisfaction of caring can be used as a risk assessment tool and that in the absence of satisfaction even small tasks become a burden (Nolan, personal communication).
- social support and networks are valuable to carers but it is not certain which components are most valuable although they are likely to be:
  - provision of information about support agencies
  - named contact person
- receipt of appropriate services by service users and carers is essential to maintaining both in their home
- financial outcome as many carers are not aware of financial benefits or do not receive them.
- physical health status as maintenance of physical health is an essential to the carer.

H42. Carers need prompt advice and information about mental illness, what it means to be a carer, the services and benefits available, and voluntary agencies. The usefulness of the information depends on the perspective adopted. Therefore carers should be asked what they think they need to know. Carers also need training in skills required for caring. It should be noted that carers needs are ongoing and will change. Even an experienced carer should not be assumed to have up-to-date knowledge and skills. In addition it is recognised that carers may not be able to assimilate information early in the caring process. The information and skill requirements of carers should be reassessed in the medium and long term. A good outcome for carers could be having their informational and skill needs assessed and being in receipt of appropriate information and training.
Outcome measures

H43. A number of specific measures have been developed to measure the impact of caring. These are listed in Exhibit H3.

**EXHIBIT H3: MEASURES OF CARER OUTCOME**

<table>
<thead>
<tr>
<th>Type of measure</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Burden</td>
<td>The Care Giver Strain Index</td>
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<tr>
<td></td>
<td>Relatives Stress Score</td>
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<td></td>
<td>The Burden Interview</td>
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<td></td>
<td>Carers Assessment of Difficulties Index (CADI)</td>
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<tr>
<td></td>
<td>Carers Assessment of Managing Index (CAMI)</td>
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<tr>
<td></td>
<td>(strictly a measure of coping rather than burden)</td>
</tr>
<tr>
<td>Stress</td>
<td>Relatives Stress Score</td>
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<tr>
<td></td>
<td>General Health Questionnaire (GHQ)</td>
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<tr>
<td>Depression anxiety</td>
<td>GHQ</td>
</tr>
<tr>
<td></td>
<td>Wakefield Depression Scale</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Carers Assessment of Satisfaction Index (CASI)</td>
</tr>
<tr>
<td></td>
<td>Carers satisfaction questionnaire (Homesat, Hopsat)</td>
</tr>
<tr>
<td>Multidimensional</td>
<td>Nottingham Health Profile (NHP)</td>
</tr>
<tr>
<td></td>
<td>GHQ</td>
</tr>
<tr>
<td></td>
<td>SF-36</td>
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<tr>
<td>Social networks and support</td>
<td>Interview schedule for social interaction (ISSI)</td>
</tr>
</tbody>
</table>

H44. Challis et al. (1994) reviewed measures of carer burden and suggested that either the Relatives Stress Score or Care Giver Strain Index could be incorporated into routine clinical practice, although both measures would require further testing of their psychometric properties in particular construct validity. They further suggested that either of these measures could be used in conjunction with a more general measure of stress such as the General Health Questionnaire. However, Nolan et al. (1995) felt that the use of such measures was too simplistic and have developed their own range of measures (CADI, CAMI, CASI). These measures require further testing of their psychometric properties.
**H45.** It should be noted:

- There are two approaches to measuring the impact of caring on carers; the use of a global measure - such as the Care Giver Strain Index, or the measurement of the individual components of burden and stress. Some of the measures in the latter approach will be relevant to service user outcomes, namely depression, anxiety, satisfaction and could form the basis of an assessment of both service user and carer.

- Carers’ perception of burden may be related to their own physical, social and mental state and other factors. An assessment of the dimensions may be more appropriate than measures of burden or stress.

- There are several measures of social support available. Carers do not live in isolation and they have a range of social networks. Although it is accepted that informal social networks are highly valuable there is no consensus on which dimensions of social support networks are essential to the well-being of carers. In addition not all support is useful (Rook 1992). Measuring outcome in terms of social support alone will therefore not be sufficient.

- Measures of finance, receipt of services, information and training are lacking.

- The measures listed are largely those used in research as opposed to everyday practice. Some measures may be impractical and costly to use in routine practice.

**Conclusion**

**H46.** Exploring the impact of caring on informal carers is important. In view of the complexity of caring and its impact on carers it may be more meaningful to adopt the approach of measuring the individual components of burden and stress rather than the global approach. However, whichever approach is ultimately adopted it is important to recognise that the outcomes for carers and those that they care for are interdependent. The outcomes for carers must therefore form an integral part of assessing and monitoring outcomes for patients with severe mental illness.
APPENDIX I: OVERVIEW OF MENTAL HEALTH MINIMUM DATA SET

Introduction

I.1 The new mental health minimum data set has been developed to supplement the information on mental health services currently available from the hospital episode statistics (HES), the common information core (CIC) and the Korner aggregated returns. The data set has been developed initially for use within the specialist secondary care mental health services, but it has been designed to be sufficiently flexible to be migrated into other settings, most notably mental health care provided within primary care.

I.2 The data set is person centred and records the packages of care received by an individual across NHS resources. It is designed around the clinical process and includes outcome assessment (HoNOS). It recognises the importance of partner agencies, most notably social services.

I.3 The data set was developed to capture information related to the planning and delivery of services (CPA), supervision registers and the new powers of supervised discharge. It will support the development of new mental health policy and the performance management of the provision of mental health services. The data set will be held in patient information systems that are either already implemented or are planned to be implemented in the period to 2000.

Users

I.4 The principal users of the data set are considered to be:

- clinicians, for whom the data set will provide comparative information on clinical practices and outcomes
- provider managers, for whom the data set will provide comparative information on patterns of resource use, the implications of alternative models of care and support performance management and service planning activities
- commissioners, for whom the data set will provide comparative information on patterns of care, quality of services and outcomes for strategic planning, monitoring and costing of mental health services.
- NHS Executive/Department of Health, for whom the data set will support accountability to the public and Parliament, policy development and analysis, securing and distributing resources for health care, strategic planning and performance management of the NHS.

Data set

I.5 The data set comprises a single record about each spell of mental health care provided to a patient by a provider, usually one record per patient. A spell begins with the first face to face contact with any professional member of staff.
of the provider unit and finishes when the last staff member currently involved with the patient ceases their involvement. The data set will be collated at the end of each quarter and each financial year (reporting periods).

1.6 The data set comprises the following areas of data:

- patient
- administrative
- assessment
- care management
- care provided.

1.7 The **patient** data comprises:

- patient identifiers
- sex
- age
- marital status
- ethnic group
- year of first psychiatric contact
- age of youngest child (for women with children under 10).

1.8 The **administrative** data comprises:

- general practitioner
- health authority
- electoral ward of residence.

1.9 The **assessment** data comprises:

- diagnosis
- HoNOS outcome score:
  - first in spell
  - most recent in spell
  - worst in spell
  - best in reporting period.

1.10 The **care management** data comprises:

- start and end dates
- key worker occupation
- source of referral
- care given without consent
- most restrictive legal status
- date last seen by key worker.
- days spent and status at end of reporting period:
  - at each CPA level
  - on supervision register
  - under legal compulsion.

I.11 The data about **care provided in a reporting period** comprises:

- NHS:
  - days in hospital by patient type
  - day hospital or clinic attendance
  - contacts with community psychiatric nurses, psychologists etc
  - treatments including ECT
  - time patterns of care inputs.

- Other care data:
  - residential - nursing home care
  - other accommodation where help is provided
  - domiciliary care
  - day centre attendance
  - sheltered work.

Scope

I.12 The data set currently relates to adult and elderly patients in contact with specialist mental health care services in England. The piloting and consultation stages of the project will explore the feasibility of including:

- high security services
- NHS patients receiving mental health services from independent providers.

I.13 The data set does not currently cover:

- patients receiving care for learning disabilities or from child and adolescent psychiatric services
- mental health services provided by primary care
- patients receiving mental health services from NHS providers in Wales, Scotland and Northern Ireland.

It is intended that these areas will be considered as possible future developments of the data set.
I.14 The data set has been constructed based upon information used in patient care. Data will be gathered at:

- patient registration
- initial assessment
- patient reviews (CPA)
- face to face contacts with mental health services staff
- Mental Health Act events.
APPENDIX J: REFERENCES


