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ORIGINAL PAPER

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A comprehensive clinical database for mental health care in England*

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Abstract *Background*: Monitoring and researching clinical care calls for comprehensive clinical databases. In mental health care these need to cover all aspects of the care of each patient and to accommodate the complexity of care which may last from weeks to years. This paper describes the pilot work for a mental health clinical database intended to be implemented throughout the English National Health Service. *Methods*: In collaboration with three pilot sites, a set of data extracts was defined which could reasonably easily be produced, mostly using existing statistical data collection systems. Software was designed to integrate these extracts into patient-based records describing overall spells of mental health care. These data were extracted from their systems for a 6-month pilot period. *Results*: Two of the three sites produced data sets, which appeared to give a reasonably complete account of the work undertaken in the pilot period. Known differences in service design and clinical perspective between the two sites were clearly reflected. *Conclusions*: The approach to extracting and collating the data is workable within existing resources and produces illuminating data for clinical audit, management and planning. Completeness and accuracy of data is likely to be a continuing problem, as for any routine data capture exercise. However, the process of integrating data from several channels assists this, as inconsistencies become apparent and can be tackled. The approach is now being implemented throughout England.

Introduction

Developments in both management and research are indicating the need for a more sophisticated approach to data collection in routine clinical practice.

Those managing and planning health services are increasingly being called upon to ensure optimal clinical outcomes and a good experience of treatment for patients, while using resources parsimoniously. In England, this new agenda is termed 'clinical governance' (NHS Executive 1998). In most areas of clinical practice, routinely gathered information lacks the patient-centred structure and clinically rich scope to monitor such goals.

At the same time, Black (1997, 1998) has recently argued that progress in clinical research work is impeded by the inevitably limited size and scope of studies based on specially collected data. While administrative data sources have been the subject of research for many years, he suggested that a new approach, combining administrative data with clinical observations, to give an analysable picture of the care received by all patients, would give a broader perspective and allow the range and complexity of the problems of real patients treated in 'normal' settings to be addressed. For mental health care research, this type of approach has particular relevance because of the multifaceted nature of both problems and interventions, and the substantial human elements influencing care outcomes. Conventionally structured studies of mental health service effectiveness (for example the UK700 study, Burns et al. 1999) commonly produce ambiguous or conflicting results. This suggests a need for data sources with much wider coverage, so that patterns of variation in rates of service usage and treatment effectiveness can be studied in their own right.

But establishing large-scale clinical databases is a complex task, as recent American, Australian and New Zealand publications on this issue illustrate (Leginski et al. 1989; Morris Yates and Andrews 1997; New Zealand Mental Health Information National Collection 1999). Detailed definitional standards covering both

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administrative and clinical aspects of recording are needed. The data items, the conceptual framework in which they are set, and the data extraction and transmission arrangements must be relevant to the wide range of administrative contexts, service delivery styles and information system arrangements in which they will need to be applied. For local health care provider organisations to make the greatest use of local data, information must also be returned from the centre in the form of benchmarks tailored to the specific types of clinical caseload found in different types of area.

The Department of Health in England has been studying the feasibility of developing a national, patient-based system for the collection of clinically focused data about all patients seen by specialist mental health services. This paper describes the principles underlying this work and presents some findings from pilot work in three sites. Its relevance is first to those developing similar data sets in other countries and second in setting out the issues involved in the interpretation of data from this type of source.

Design and key considerations

Specialist mental health care in England is provided jointly by local health service units (called 'Trusts'), which provide medical, nursing, psychology and other types of treatment service, and Social Services departments of local government, which provide or organise a range of residential, occupational and other supportive services. Both types of agency have largely geographically defined, though seldom coterminous, areas of responsibility. Ideally, the data set should combine details of all the types of intervention received by each service user. In practice, in most places these are currently documented on several computer systems in both types of provider organisation (Glover and Sinclair-Smith 2000), necessitating a data assembly process.

The task of joining the several data streams for each patient could either be done at the local care site or at a central collation department (the strategy adopted in the recent New Zealand model; New Zealand Mental Health Information National Collection 1999). Experience in an earlier pilot study (Glover et al. 1997) indicated that requiring local services (where problems could be rectified) to undertake this linkage was more likely to work. This made the local health services the leading agency for the work.

The data set took as its basic record a 'spell of care' for a patient. This is defined as the time from when a patient first has contact with the specialist service to the time when they are discharged with no further care anticipated. Within the period for which national data are likely to be produced (a year), a few patients may have more than one spell of care. These situations are clear from the patient identifiers, and spell records can be combined where appropriate, thus allowing for both patient- and spell-based analyses.

The choice of data items for care spell records was limited by practicalities of data collection. Basic socio-demographic details and simple details of most types of contact with Health Service staff were readily available from existing information systems. Data relating clinical assessments and treatments required detail from clinicians not currently recorded for statistical purposes. Most difficult were data about social care interventions (supportive accommodation, day centres, and domiciliary care workers), provided either by Social Services partner agencies or by completely independent organisations. Data on these were collected through the process of Care Programme Approach (CPA) reviews. The CPA is a quality standard, required by the Department of Health, for patients of specialist mental health services. The protocol, intended to improve the co-ordination of the various agencies caring for mentally ill people, requires that all patients receive an initial assessment of their care requirements, a written care plan, an identified key worker and regular reviews. The wider data items were obtained from databases of CPA care reviews. A full list of the data items is shown in Table 1.

Pilot study

Pilot work was undertaken with three mental health care provider Trusts, each responsible for a defined population. These were chosen to reflect the range of service and information system configurations in which the data set would need to be viable. Trusts were required to collect all data items routinely for a 6-month trial period from December 1997 to May 1998 using, as far as possible, their normal information systems. Computer software was provided to assemble it into the required care spell format on the basis of consistent rules.

We hypothesised that:

1. Reported volumes of services delivered would reasonably accurately match recent statistical returns by the Trusts.
2. Reported volumes of activity would reflect numbers of available staff and facilities.
3. Most activity would be linkable to individual patient identifiers, which could in turn be linked to basic socio-demographic data, thus providing the basic characteristics of a large-scale case register.
4. The collated data would reflect local clinical service patterns, intelligible in the light of local clinical policy and experience.

Results

Hypothesis 1: comparison of reported service volumes with national statistical returns

Volumes of the major components of activity were compared with Department of Health returns for the year

Table 1 The mental health minimum data set. Each record represents the part of a single Mental Health Care Spell, for a patient, which falls within a specified reporting period, usually a year. Where a mental health care spell lasts longer than the reporting period, parts of it will be recorded in successive annual returns. Where care items are marked Y/N, the item records only the presence or absence of a type of care, not the volume provided to the patient (*CPA* Care Programme Approach, *HoNOS* Health of the Nation Outcome Scales)

Patient details

1. Sex
2. Date of birth
3. Marital status
4. Ethnic group

Administrative details for patient

5. Local patient identifier
6. NHS number
7. Health authority of patient's residence
8. Local authority electoral ward of patient's address
9. GP practice code

Administrative details for care spell

10. Spell number in period
11. Mental health care spell start date
12. Source of referral
13. Mental health care spell end date
14. Code for how care spell ended
15. Days of mental health care spell in reporting period
16. Consultant's specialty

CPA and legal status

17. CPA level at end of reporting period
18. Days of minimal CPA in reporting period
19. Days of more complex CPA in reporting period
20. Days of full multi-disciplinary CPA in reporting period
21. Key worker's occupation code
22. Date last saw key worker
23. Days on supervision register within reporting period
24. Supervision register status at end of reporting period
25. Days liable for detention within reporting period
26. Days subject to supervised discharge within reporting period
27. Legal status at end of reporting period
28. Most restrictive legal status in reporting period
29. Care without patient's consent under section 58 (Y/N)

Assessment and progress

30. Recent diagnoses (up to 6)
31. First HoNOS in mental health care spell (with date)
32. Most recent HoNOS in mental health care spell (with date)
33. Worst HoNOS in mental health care spell (with date)
34. Date of best HoNOS in last 12 months (with date)
35. No. of Mental Health Act assessments within reporting period
36. No. of community care assessments in reporting period

Care interventions

Hospital and residential

37. Psychiatric in-patient days within reporting period
38. Medium secure in-patient days within reporting period
39. Intensive care in-patient days within reporting period
40. Days of acute home based alternative to in-patient care
41. NHS community bed days
42. Non NHS funded residential or nursing home (Y/N)
43. Other accommodation where care is provided (Y/N)
44. No. of admissions to in-patent care within reporting period
45. No. of discharges within reporting period
46. In-patient stay lengths
47. Community survival times (intervals between admissions)

Day care

48. Attendances at NHS day care facility
49. Indicator of use of non-NHS day centre care (Y/N)
50. Sheltered work indicator (Y/N)

Table 1 (Contd.)

Consultations and community contacts

51. Psychiatric consultant out-patient clinic attendances
52. Community psychiatric nursing contacts
53. Clinical psychology contacts
54. Occupational therapy contacts
55. Psychotherapist contacts
56. Physiotherapy attendances
57. Social worker contact (Y/N)
58. Social services domiciliary care (Y/N)

Treatment

59. Mental health treatment procedures
60. No. of administrations of electro-convulsive therapy within reporting period

from 1 April 1997. This is not the totally circular comparison it appears to be, despite the fact that Department of Health returns are produced in part from the same information systems. It was designed to quantify the extent to which the computerised data capture systems were actually supplemented by ad hoc arrangements for specific activities not conveniently recorded on the systems. This set of Department of Health returns is also the subject of detailed scrutiny, as it is used for contract monitoring. Thus it forms something of a gold standard.

In the data for site A, where a new information system had been installed relatively recently, all aspects of clinical activity except clinic attendances to see doctors showed a substantial (50–70%) shortfall or were wholly absent. Data relating to nurse and day hospital contacts showed a rapid build-up during the study period, indicating that most parts of the system had not in reality been implemented as early as system managers thought. This data set was judged too incomplete to be useable.

For sites B and C, in-patient data showed occupied bed numbers close to recent Department of Health returns. Numbers of clinic attendances to see doctors or contacts with psychologists and occupational therapists recorded were 10–20% lower in the data extracted for the study than in Department of Health returns. These deficits resulted partly from activity in settings where staff report contact totals on paper rather than making computer records of individual events, and partly from activity with children, not covered by the data set, but which could not be separately identified in the Department of Health figures. Day hospital activity for site C was under-recorded by a larger margin (70%), perhaps reflecting the need to recover these figures from handwritten attendance books, as the computer systems did not cover them.

Thus, with one exception, hypothesis 1 was reasonably satisfactorily met in sites B and C, though it is clear that sites are likely to have specific data capture issues to address, even where systems appear to be comprehensive.

Hypothesis 2: activity in relation to staff numbers

The second hypothesis was that the reported volume of activity would reflect a reasonable workload for the numbers of staff and facilities available to undertake the work. Simple ratios of activity per staff member were calculated. In site B, doctors (in clinic attendances) saw 5.1 patients per week, community psychiatric nurses (CPNs) 12.2, psychologists 7.8 and occupational therapists (OTs) 18.9. Figures for the available numbers of CPNs in this site were partly estimated, as some nurses' time was shared between ward and community work. For site C, corresponding figures were doctors 6.7, CPNs 14.2, psychologists 22.7 and OTs 40.1. The figures for doctors from both sites seem low, although it is not clear exactly what they should be. Some junior doctors spend most of their time working in in-patient or day-hospital settings not attributable to specific patients, and the figures presented here did not cover visits by doctors to patients in their homes. It may also be that data from some outlying clinics, perhaps in general practitioner (GP) surgeries, was omitted. The difference in figures for OTs is considerable, suggesting possible differences between sites in the way group sessions were recorded. Figures for psychologists are more difficult to interpret, since in England these staff work extensively through secondary consultation with nurses, social workers and other professionals – a style of activity not reflected in patients' contact statistics. Allowing for this, figures for site C look plausible, those for site B look incomplete.

Bed occupancy was calculated in relation to numbers of available beds (Department of Health 1997). In site B, 131 beds were available for patients aged 16–64. Activity recorded in the data set accounted for 95.5 (72.9% occupancy). For older patients, 27 beds were available and activity accounted for 25.7 (95.0% occupancy). In site C, 98 beds were available for patients aged 16–64. Activity recorded in the data set accounted for 88.6 (90.4% occupancy). For older patients, 112 beds were available and activity accounted for 81.5 (72.7%). These occupancy rates were close to those published for the whole year by the Department.

Thus the second hypothesis was less satisfactorily met. In the case of in-patient activity, it mirrored other estimates. For staff activity, the key conclusion was that this, apparently sensible proxy measure of completeness, was much less easy to test than anticipated.

Hypothesis 3: linkage of data to a master patient index

The development of a master patient index is central to linking the data where it is drawn from several sources. Its central importance is that it provides a starting point for consideration of the completeness of information about all aspects of patient assessment and care.

In site B, extensive work had already been done on marrying the two major computer systems in use as part of the implementation of the new format National Health Service (NHS) number (NHS Executive Information Management Group 1993). Of the eventual master patient index entries for the 7353 patients with a spell of care in the relevant period, all recorded the patient's sex, over 99% included dates of birth, 92% a postcode (needed to assign patients to administrative geographic areas with known population sizes), and 99% the patient's GP. Marital status and ethnic group were recorded only for 66% and 46% respectively. With the exception of the patients postcode, data were generally more complete for patients using more intense care.

In site C, data came from four information systems with two separate numbering formats. The final master index, to which all recorded activity linked, contained 3655 patients with a possibility that up to 5% might have been duplicate entries. Full age and sex data were available on 92%, postcodes on 55%, marital status on 56%, ethnic group on 59%, and GP on 67%. Marital status, ethnic group, postcode and GP data were found on CPA review and in-patient data. Completeness broadly reflected patients covered by one of these sources.

Hypothesis 3 was, again, partly satisfied. In sites B and C it proved possible to produce a master index with reasonable confidence that duplication was absent or limited. In site A this issue was greatly facilitated since the new system was centred around a single master patient index. The poorer completeness of marital status and ethnic group data in sites B and C probably reflected a lower perceived relevance of these data items in actual care delivery.

Hypothesis 4: patterns of clinical care

Hypothesis 4 is more open ended. One issue is discussed here: the numbers of people receiving a service. In site B, 7353 patients were in touch with the service, and between them received 7500 care spells in the 6-months – prevalence of 24.1 patients per 1000 total population. In site C, 3655 received 3692 care spells – a prevalence of 14.8 per 1000.

Table 2 shows more detail of this pattern in the two sites for adults aged 16–64. While very different in overall prevalence of care, the sites (which are fairly similar in terms of deprivation characteristics) have nearly identical rates of spells involving 'complex' care, i.e. in-patient, day hospital, or ambulatory care with more than one clinical discipline. The larger bottom-line figure in site B arose partly from much larger numbers of patients receiving care from a CPN alone, and partly from the technical issue of more spells with no recorded clinical activity. The first difference reflects site B's local policy commitment to accessibility, in contrast to site C's aim of focussing all available resources on the severely mentally ill. At this simple level, hypothesis 4 is satisfied.

These figures compare well with treatment prevalence figures derived from psychiatric case registers. Sytema et al. (1989) cite 1-year prevalence figures of 11.1 patients for Verona and 31.5 patients for Groningen per

Table 2 Care spells per 1000 population for patients aged 16–64, by the type of case received. Figures in parentheses are 95% confidence intervals; figures in italics are subtotals or totals

Care	Site B	Site C	Ratio B/C
Complex care[a]			
In-patient	1.8 (1.9–1.7)	2.4 (2.5–2.3)	0.7
Day hospital care	0.3 (0.4–0.3)	0.3 (0.3–0.2)	1.2
Mixed consultation	4.0 (4.1–3.8)	3.3 (3.5–3.2)	1.2
All complex	*6.1* (*6.2–5.9*)	*6.0* (*6.2–5.8*)	*1.0*
Simple care[b]			
Clinic visit to doctor	2.5 (2.6–2.4)	2.7 (2.9–2.6)	0.9
Community psychiatric nurse	9.3 (9.6–9.1)	2.5 (2.6–2.3)	3.8
Clinical psychologist	0.7 (0.7–0.6)	1.3 (1.4–1.2)	0.5
Occupational therapist	0.6 (0.7–0.6)	0.4 (0.5–0.4)	1.4
Other therapists	0.7 (0.7–0.6)	0.2 (0.3–0.2)	3.1
All simple	*13.8* (*14.1–13.5*)	*7.1* (*7.3–6.9*)	*1.9*
Any care	*19.9* (*20.2–19.5*)	*13.1* (*13.4–12.8*)	*1.5*
No contacts	6.9 (7.1–6.7)	1.6 (1.7–1.5)	4.4
All on books	*26.7* (*27.1–26.4*)	*14.7* (*15.0–14.4*)	*1.8*

[a] Care package including more than one clinical discipline. Patients in this group are assigned to the highest level of care used, with in-patient first, day hospital second and mixed consultation third
[b] Consultations with one clinical discipline only

1000 adult population. Six-month prevalence figures (which would be expected to be a little lower) were 22.9 patients in site B and 16.4 patients in site C per 1000 adult population. Fryers and Wooff (1989) described 1-year period prevalence figures from the Salford case register in Greater Manchester by 10-year age bands. In the latest year they describe (1986), apart from patients under 25 and over 75, these rates ranged from 26 to 32 per 1000 population in the age group. Six-month prevalence figures for patients aged between 25 and 54 from site B were similar. (23–24 per 1000), while figures for patients aged between 55 and 74 were lower, at 14–17 per 1000. Older and younger people showed similar patterns. Rates from site C showed a similar profile, but at a lower level.

Discussion

Quality and completeness of the data

The data were predictably incomplete, particularly those items that had not previously been the subject of statistical returns. Experience from the introduction of other new formats of national data gathering (most notably psychiatric Hospital Episode Statistics in 1986) would suggest that completeness will rise over the first two to three years of actual collection. The raw data format of the data set makes incompleteness more obvious, and creative manipulation intended to present services in an unwarrantably favourable light much harder.

The largest source of incompleteness was data sought from CPA reviews. Some data capture point where clinical staff will set out assessments and care plans cannot be avoided if these dimensions of meaning and purpose are to be encompassed in the data set. However, the concept of a mandatory formal review structure with associated data collection is still relatively recent and to some extent controversial in the English Health Service, having arisen in a context of criticism of current practice (Tyrer and Kennedy 1995). It is perceived by some clinicians as onerous, particularly in application to less severely ill or disabled patients. New guidance requiring Trusts to establish electronic patient records of these review conclusions (NHS Executive 1999) to assist clinical co-ordination may help.

The project did not have the resources to test directly the accuracy of the data collected. Other studies have demonstrated how the Health of the Nation Outcome Scales (HoNOS) perform in near routine circumstances (Wing et al. 1996; Trauer et al. 1999; Bebbington et al. 1999; Sharma et al. 1999; Amin et al. 1999; Slade et al. 1999). However, the completeness and accuracy of routine data sets cannot be ascertained once, for all time. Errors will vary between Trusts and over time. As with all national statistics, these aspects of quality will need long-term monitoring and occasional corrective interventions. The linkage between the various parts of the data set makes testing its completeness a little easier, as a range of questions about the likely service provision to specific groups of patients can be explored.

The project worked within a fairly tight timescale, necessary to the funding organisation. This contributed to some incompleteness; for example, the HoNOS training programme in one site was still running well into the data capture period. Trusts' early problems in assembling data from their various systems, which would ideally have been sorted out prior to the start of the pilot periods, took time and resources originally earmarked for improving data quality and working with clinical managers on the local interpretation and use of the data.

The project experienced at first hand the rapid turnover of information technology (IT) staff and facilities in the health service. During its course, the key information officer changed in all three pilot sites – in one site twice. In two out of the three Trusts, the IT arrangements were simultaneously undergoing rapid transition. This level of change is likely to pose more problems as the introduction of electronic patient records makes information support more central to clinical activity, and as the current wave of mergers between neighbouring Trusts necessitates integration of the different inherited computer systems.

However, in all three sites in the present study, data were recorded by the full range of clinical and administrative staff, in the course of their daily work.

Use of the data

For the two sites that produced data, all the adult and elderly services provided by the Trusts to a whole population were covered. It was pleasing to note that, despite its weaknesses, the data demonstrated clear differences between the activity in sites B and C, which could be related to differences in service design and philosophy. It also provided numerical markers of significant management issues. Long ago, Yates (1982) noted the capacity of routine data sets, with their wide coverage and large volume, to do this despite their imperfections.

The process of linking data from different sources enhances this, making it possible to explore how consistently events that should follow each other, actually do. For example, in one site it was apparent that a substantial group of patients (local residents) received no follow up after discharge from hospital – a pattern calling into question the appropriateness of some elements of bed use in the Trust. While neither the admission records nor the contact records scrutinised to identify follow-up is new, their linkage around the patient in the data set reveals these wider patterns. Other explorations undertaken covered the relationship between patients' problem and severity scores and the amount of services they consumed, and the implications of population projections for service demand, assuming unchanged problem prevalence and usage per patient. In both cases, the linkage of all aspects of service activity to the individual patient opened a new range of analytic possibilities.

Relevance of the study

At the same time as this study was being undertaken, work to address the same set of issues was in progress in Australia and New Zealand (cited in Introduction). A recent declaration by the Council of the European Union called upon member states to 'secure collection of good quality data on mental health and actively share it with member states and the Commission' and invited the Commission to 'develop and implement, as part of the Commissions health monitoring system, a component for mental health .... '.

The development of information about mental health problems, needs and service use in populations is an area of increasingly widespread interest. Probably many reasons underlie this; the widely quoted evidence in a recent World Bank report that mental health problems account for around 10% of the total cost burden of illness is the most obvious.

Inevitably, the specific results of research and development studies are most interesting in the immediate context in which they are undertaken. However, the present study offers a number of general observations of wider relevance. The difficult problems were practical not theoretical.

No new data collection strategy has the luxury of a clean slate of information systems. There is always a legacy of systems designed for different purposes. If the system is to be rolled out nationally, it is unlikely to be possible to scrap all existing systems and start again. At least the core of the information to be gathered thus needs to be feasible within the data systems already found in most local services. This places limits on the scope of the data that can sensibly be requested.

In England, the information system arrangements most commonly seen reflect the historical development of requirements for statistical reporting, and more recently billing, in the National Health Service. In other countries, different patterns of accountability to funding, overseer and administrative bodies will have produced different patterns of information system. However, in any country there is likely to be some pattern, with a reasonably consistent definitional framework, as a result of local reporting requirements. For England, even though the statistical and billing reports required over the last decade were not formulated as comprehensive person-based accounts, their production drove the development of data systems collecting person-based raw data. The key task was thus to work out a practically feasible way of collating all the data about each person from these systems.

For an initiative of this type to succeed, it is necessary to sustain support for it within the relevant government department. Given the timescale involved, this is difficult. This data set took 5 years from the inception of the first, less successful, pilot exercise (Glover et al. 1997) to the final approval of the data set described here. In that time, England has had a change of government, with profound implications for many aspects of health policy. As a result, a number of the considerations central to the inception of the work were irrelevant by the time of its completion. A number of details of the data set may need to change in response to this type of development. This is relatively unimportant, as detailed additions and modifications will in any case continue to be made to any data set after its implementation. The crucial consideration is whether the underlying framework gives a sufficiently general representation of the care being provided to be robust to such modifications.

The task of data set development has many facets. To complete it requires an understanding of the nature of the clinical work concerned, the organisational arrangement of services, the nature of data currently collected and why it is required, the technical arrangements for data collection in local services, and the data dictionary and data modelling framework for the country's health statistics into which the system will need to be fitted. No single individual is likely to have a full complement of these skills. The process is likely to be speeded by assembling from the outset a team that includes them all.

Conclusion

The aim of the project was to devise a method by which a person-based clinical database could be constructed for mental health care. Constraints were that it should be derived from data that was currently or could forseeably be collected as a matter of routine throughout mental health services in the English NHS, with little if any additional bureaucratic burden on clinical staff and very limited cost. This has largely been achieved. The approach devised is currently being implemented throughout England.

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Glossary

NHS Trusts – Organisations responsible for providing hospital- and community-based specialist health care in the English National Health Service.

CPA – Care Programme Approach. A quality standard in the English mental health services. It requires that every patient in touch with specialist mental health services should have an initial review, a written care plan, an identified key worker and periodic subsequent reviews.

MHMDS – Mental Health Minimum Data Set. A new set of data about personal characteristics, problems, interventions and progress for people receiving care from the specialist mental health services in England.

HoNOS – Health of the Nation Outcome Scale. A scoring system for 12 aspects of an individual's health and social functioning, indicating the extent to which each is impaired by mental health problems (Wing et al. 1996).

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