Setting up a psychiatric case register

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Case registers have very little to do with computers or any other form of mechanical calculating machine. To write an article on case registers which concentrated on information technology would be as logical as an article on open heart surgery which confined itself to the finer points of scalpel technology. The creation of a case register is as simple or as complicated as the clinician wishes it to be; a case register at its purest is simply a list of contacts with patients, organised to a predetermined format, which allows the clinician to gain information from the list for education, research, planning or administration. The work needed to establish a case register, however, should not be underestimated, and the time spent in thinking through reasons for development of a register is a worthwhile investment. An understanding of the history of the development of psychiatric case registers may help those wishing to develop new registers to avoid treading well worn cul-de-sacs, while reviewing some of the work which has resulted from case registers may demonstrate the enormous potential of a well-designed register in facilitating the extension of knowledge about treatment and provision of services.

From a more secure knowledge base of the domain of case registers, an exploration of some key decision points enables the clinician to formulate the relevant questions to ask when considering establishing a case register. More importantly, perhaps, it may help to make the decision that establishing a case register was not the answer to your question.

What is a case register?

A formal definition of a case register contains many elements. Wing (1989) described a case register as "a local information system that records the contacts with designated social and medical services of patients or clients from a defined geographical area. This information is stored in a linked and cumulative file so that the care of any individual or group can be followed over time." Fryers (1984) included other terms: "a prospective, cumulative, population-based aggregate of linked records of individual-orientated data, collected in a systematic and standardised form."

The basic principles of case registers contained in these definitions are summarised in Box 1. These were the common factors linking the initial British psychiatric case registers which were at the forefront of development in the 1980s.

History of case registers

The history and development of case registers is expertly documented by Fryers & Greatorex (1992) who describe the social, political, professional, and technological factors which motivated the original creation of psychiatric case registers (Box 2).

The Joint Inter-register Committee of the UK Registers, which met from 1980 to 1986, represented the nine major registers which existed in the UK (Box 3). These registers, which set many of the standards for inter-register cooperation, were

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Box 1. Key elements of case registers

Person-oriented
Cumulative
Records are linked
Multi-agency
Population based
Geographically defined

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> **Box 2. Factors influencing the development of case registers**
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> **Social:**
>   alternatives to asylums
>   community psychiatry
> **Political:**
>   planning needs
>   evaluation of effectiveness
>   activity measurement
>   availability of funding
> **Technological:**
>   advances in computing
>   increased clinician awareness
> **Professional:**
>   expansion of mental health workers
>   research interests
>   personal enthusiasm

funded from a variety of sources, and withdrawal of funding resulted in a progressive closure (Camberwell closing in 1985, Worcester in 1986 and Nottingham, Salford and Southampton in 1987).

A review of the state of case registers in the UK in 1991 (Wood & Sinclair, 1992) showed that few of the original registers had survived as stand-alone registers, but that a variety of clinical information systems with a case register function were in existence.

Most of the systems identified in this survey were for use in general adult psychiatry; some specialist areas such as forensic psychiatry, child and adolescent psychiatry and psychiatry of old age were also represented. Most of the systems were using simple microcomputers, were inexpensive, and had been developed by clinicians rather than professional programmers.

The case registers which have survived provide a major resource of longitudinal data for research; however, the information demands on the NHS in the next decade mean that planned systems will have to meet a different set of needs from those of the past, and funding may not be available for pure case registers.

What can case registers do?

The benefits of case registers are summarised by Wing (1989): "Psychiatric case registers can provide information at many different levels and in many different forms – about individuals, about groups with particular characteristics, about service units or agencies, about staff, and about forms of care."

The contributions of case registers to planning, and to epidemiological, administrative and operational research, were discussed extensively in 1986 (Ten Horn *et al*, 1986) from a European perspective, and some three years later the contributions of UK case registers to health service planning and research were reviewed (Wing, 1989).

The nature of the contributions from case registers was determined by the format of the registers and the type of data collected; the output from these registers was necessarily descriptive, statistical detail of use of the service. Evaluation of the effects of changes in the service and changes in the users of the service was possible within the confines of the accuracy of the data collected.

Case registers have been used to investigate specific questions about service delivery. Low & Pullen (1988) used a case register study to demonstrate that, when compared with hospital-based out-patient referrals, primary care clinics have more patients with a less severe illness and fewer patients with psychotic illness.

The Grampian Psychiatric Case Register, which recorded all referrals to the psychiatric services in Aberdeen, was used to investigate changes in referral rates following community psychiatric nurse (CPN) attachment to a primary care team (Wells *et al*, 1992). This study was able to use case register data for the two-year period before the CPN attachment and compare this with the three years after the attachment, and demonstrated that referrals to hospital services may be reduced by CPN involvement in primary care.

More general investigations have also been possible. Sytema (1991) investigated case register data on factors affecting psychiatric admission rates in 34 administrative areas of the Netherlands, and demonstrated the effect of environmental factors in precipitating admission.

> **Box 3. The original UK case registers, 1980–1986**
>
>   Aberdeen
>   Camberwell
>   Cardiff
>   Edinburgh
>   Nottingham
>   Oxford
>   Salford
>   Southampton
>   Worcester

Box 4. Benefits of case registers

Provide comparative epidemiological data
Allow evaluation of service change
Provide a research resource
Provide a planning resource
Promote standardisation of classification
Have potential for multi-agency contact
recording

The concept of a case register has much to offer to planners, clinicians, and researchers (Box 4) in terms of a resource for health care planning, evaluation, and delivery. The case registers which still operate in the UK and Europe are valuable centres for research in mental health, and continue to contribute towards many areas of planning and development from an epidemiological viewpoint. The potential for innovative use of case registers in service planning can be illustrated by the system described by Stefanson (1984). This combined data from a psychiatric case register with demographic data, and then processed the information through a computerised map analysis system. This provided information about the geographical distribution of diagnostic categories and service use in a readily understandable graphic format for planning and evaluation purposes.

Their limitations

The limitations of case registers arise not from defects in the registers but from their limited remit (Box 5). The contacts are only recorded for the agencies which participate in the register and have tended to exclude primary care contacts. People who are not in contact with recognised agencies

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Box 5. Limitations of case registers

Contacts limited to participating agencies
Contacts limited to geographical area of
register
Diagnostic inaccuracy
Financial support unreliable
Not clinician-friendly
Privacy and confidentiality issues

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are not recorded, and with a mobile population and a small geographical register area, loss of contact with the register may be difficult to interpret.

The accuracy of information in the system may be variable, with diagnosis being particularly unreliable (Goodman *et al*, 1984; Wing, 1989).

Early case registers tended to be inaccessible to the clinician; routine questioning of the case register was a complicated process, resulting in a loss of a feeling of participation in the register by contributing clinicians.

The issue of confidentiality and privacy has been a central concern for case registers. The privacy laws of some countries make the establishment of registers very difficult; elaborate systems have to be devised to match entries on the register with a minimum of personal data available.

The funding sources of case registers have historically been insecure and not tied in to the main business aims of the NHS, being seen as a peripheral and dispensable add-on rather than a core essential of health care delivery.

The future of case registers

The technological advances in computing over the last ten years could enable the development of larger, faster, more efficient case registers. The changes in the NHS over that same period have produced a health industry which has significantly different information needs from those that can be provided by case registers or any other isolated task-specific system.

The NHS information technology strategy has undergone a revolution to come to terms with the new reality of the NHS, and has developed a set of guiding principles which will be the foundations of any developing information systems in the future (Box 6).

These principles see information systems as being clinically based and used as clinical tools, but collecting management and other information as a by-product. The systems will avoid duplication of entry of personal data and will allow sharing of information across agencies, while ensuring the privacy and confidentiality of the information.

The elements of the NHS strategy are derived from a series of projects which aim to form the framework for the new information systems. The NHS number replacement project, which will give all patients a unique nationally-recognised identifier, will aid communication across systems and open up new possibilities for epidemiological

research. The clinical terms project, which aims to provide terms representing preferred clinical concepts, agreed synonyms and eponyms for these terms, and agreed abbreviations, will provide a system for ensuring compatibility of information systems. It is from these sub-projects that an environment to foster information-sharing will evolve, making the development of new forms of case registers possible.

The clinical focus of all these developments is designed to ensure that the information needs of purchasers and providers (for recording activity, planning needs and management information) will be derived from clinical systems that meet clinical needs.

The training needs of clinicians in the use of information and information technology have been recognised within the NHS strategy, and are to be met through the work of the National Information Management and Technology (IM&T) Steering Committee and its clinical steering groups. Training in conjunction with more clinically-orientated information systems may lead to an increase in development work, with great potential for directing and supporting changes in service delivery and resourcing.

The establishment of new case registers will have to be within this NHS strategic framework and will have to follow the principles outlined. When these principles are compared with the aims, benefits and limitations of case registers, a way forward appears which may overcome some of the limitations and increase some of the benefits. It is evident that the creation of stand-alone case registers, such as those of the last 20 years, is neither desirable nor feasible.

The virtual case register

Computerised clinical case records in psychiatry are now readily available. Reviews of their use (Rohde & Taylor, 1992) show that they are acceptable to clinicians and can be used as the clinical
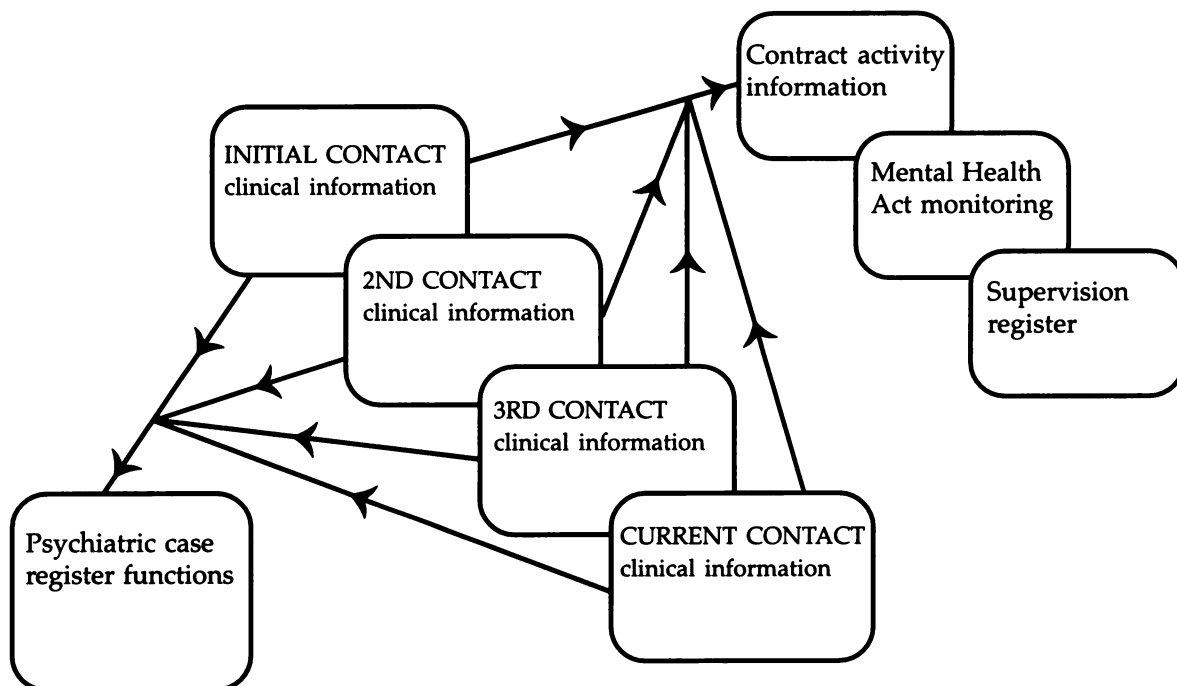

Fig. 1 A clinical system functioning as a case register and management information system

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Box 7. Decisions to be made when implementing a computer system

What is the system for?
Can a dataset be agreed?
Who operates the system?
Who collects the data?
Which system should be used?
How many terminals and where?
Who maintains the system?
Who funds the system?
Who has access to the information?
Who manages the change?

Box 8. The ideal mental health system

Information included:

    Local history, topography and
      communications
    Sociodemographic indices and
      epidemiology
    Local services
    Clinical data
    Opinions of users and carers

Functions:

    National returns
    Regional returns
    Resource allocations and target setting
    District needs and outcome assessment
    Casemix
    Care plans
    Clinical records
    Clinical audit
    Monitoring and reporting

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core of a larger system as envisaged in the NHS strategy.

The ability of such systems to archive information and to link it within and across agencies raises the possibility of a psychiatric case register which is a concept rather than a reality – a virtual case register (Fryers & Greatorex, 1992).

The concept of the virtual case register is simple in that it sees clinically-based systems that are used as everyday clinical tools as the core of an information system, which then reorders the information into the form needed for a case register. The clinician can be presented with a clinical workstation that delivers information on current clinical records and allows interactive interrogation of the information for research or planning. The case-register aspects of the system remain within the system, and are a product of the primary clinical role of the workstation rather than its primary function.

The information from the clinical system is stored in an archive and can therefore be retrieved as a sequence of sets of information for each contact with the system (Fig. 1).

Coupled with advances such as decision support systems (Taylor, 1992), a total mental health information system becomes a tool for the use of clinician, researcher, manager, purchaser, provider and planner. With its funding linked in to the prime need for activity and outcome information, the historical financial instability becomes less of a threat.

To succeed, such a system has to be built within the present NHS strategic framework and has to address the needs for common data sets, standardised information interchange protocols, inter-agency information-sharing protocols, coding and diagnostic classification issues, and the prime need for maintaining privacy and confidentiality.

The way ahead

Psychiatric case registers should be seen as a developmental stage of mental health information systems. The benefits of such registers can be obtained from within well-planned clinically-based information systems. Those considering establishing a case register should review their intentions and use the present NHS IT strategy proposals as a framework to ensure that planned clinical systems will deliver a case register function as part of their day-to-day activity.

The steps to be taken in considering establishment of a mental health information system are clearly discussed by Rhode & Taylor (1992)(Box 7).

The target to aim for in establishing the ideal system has been outlined by Wing *et al* (1992)(Box 8) and should be used as the terms of reference for any group involved with taking the psychiatric case register forward into the new millennium.

The psychiatric case register has been an important step in the development of systems which will meet the information needs in the future. However, the way forward is not to clone replicas of evolutionarily redundant species; the new world requires a new "information animal" more allied to the chameleon than the dinosaur.

The role of the clinician in this process is to ensure that at national and local level the clinical needs of information systems are seen as paramount, and that the principles of the NHS strategy are known, understood, and followed by all involved. The incorporation of a case register function within the overall system should then become an integral part of the system design from the outset, rather than a fragile and easily pruned appendage.

Acknowledgements

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Multiple choice questions

1 Case registers are defined as:
a retrospective
b unlinked
c population-based

2 The original nine major UK psychiatric case registers are:
a mainly closed
b still operating
c all closed

3 The NHS IT strategy includes:
a management-centred systems
b duplicate information entry
c person-based information systems

4 A virtual case register:
a is a concept rather than a system
b is not clinically based
c contains only current clinical data

5 The establishment of case registers is made most difficult by:
a the Data Protection Act
b privacy laws
c access to health records legislation

MCQ answers

1		4	
a	F	a	T
b	F	b	F
c	T	c	F
2		5	
a	T	a	F
b	F	b	T
c	F	c	F
3			
a	F		
b	F		
c	T		