

Monitoring the outcome of care for children with specific problems in England

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1 Background

1.1 This note is intended to be read in conjunction with the paper 'Monitoring clinical performance: a statistical perspective'¹ prepared for the Bristol Royal Infirmary Inquiry. It discusses in greater detail the extent to which initiatives under way in England are moving in the direction advocated and queries whether the resources available are adequate to achieve their aims.

1.2 To monitor the health of children with specific problems, a population based approach is needed. This would focus on the children and the care they receive, irrespective of whether they do or do not receive particular interventions. It would also ensure that when the outcome of particular interventions is being evaluated, data are available about pre-existing health status and risk factors.

1.3 There is a wide gap between this ideal situation and current reality, but many initiatives already proposed or under way would lead us in the right direction.^{2,3} Work is already under way to link the current fragmented systems and a more integrated approach is being planned for the future in England, Scotland and Wales.⁴⁻⁶ It is unclear, however to what extent the resources available are adequate.

2 Current initiatives

2.1 The information strategy for England, *Information for health*, and its counterparts in other countries of the United Kingdom propose moving to a situation where information is collected once only and records are linked together using NHS numbers.⁴⁻⁶ Electronic patient records will bring together information about care which people receive within a given trust. Information about care which people receive from NHS and social services will be brought together in an electronic health record.

2.2 The Department of Health envisages in *The NHS plan* that by 2004 75 per cent of hospitals and 50 per cent of primary care trusts will have implemented electronic patient record systems.⁷ Many people consider this target very ambitious and the *Plan* does not make it clear what resources will be devoted to this.

2.3 Since 1 October 2000, general practitioners are no longer required to keep paper records and are instead given a choice between keeping records in paper or electronic format.⁸ Although this is a positive move towards electronic health records, this presupposes that the computer systems concerned have facilities for aggregating information and summarising it in a statistical form.

2.4 Currently no data are routinely collected from the private sector, so its performance is not monitored. This is a major problem, given the recent concordat between the NHS and the private sector. The Care Standards Agency and its counterparts in other UK countries, should use its powers under the Care Standards Act to require private hospitals, nursing homes and residential homes to collect much fuller data and contribute them to national systems.

2.5 An integrated approach would mean that clinicians in particular subspecialities such as cardiac surgery could have clinical systems linked to their hospital's administrative system. They would not have to waste their time re-entering names and addresses, which would have already been entered by other staff and could concentrate on entering clinical data. These could, in turn, be fed into HES records via the administrative system. This contrasts with a situation based on stand alone systems, where data are often entered more than once and data collected during the course of clinical care may never get into national systems.⁹ A critical issue, however, is the quality and reliability of information in patient administration systems and whether they are adequate for the task.

2.6 It should also be possible to use the NHS network to set up specialised national systems to bring together more detailed data about specialist activities, such as paediatric cardiac surgery, at a national level into national databases owned by the speciality.

2.7 Up to now, it has been difficult to link data about babies as NHS numbers have not been allocated until the parents register the birth, which can be up to six weeks after it occurs. This situation is changing as the NHS Information Authority is now implementing a new system to issue NHS numbers at birth.¹⁰

2.8 Clinicians often do not feel ownership of data in national systems, despite their increasing involvement in developing coding systems, as was done with Read codes. The approach being used by the NHS Information Authority in its Maternity Care Data Project is to ask each clinical group involved to define the data items which it wants to collect. This is particularly important in the area of maternity care, where there are many different clinicians involved, including, midwives, obstetricians, obstetric anaesthetists, paediatricians and neonatal nurses. The data items are then being brought together in a common data dictionary and systems suppliers will be expected to use this in the future.¹¹ If successful, this approach could be extended to other areas of care.

3 Disease registers and monitoring the health status of children

Most of the work on follow-up of children has related either to following up those born too soon or too small or in following up those involved in randomised trials.¹²⁻¹⁴ Systems for monitoring congenital anomalies are known to be incomplete at a national level and work is under way to improve them, notably by taking data directly from local registers, where they exist.^{15,16} These cover only about half the area of the United Kingdom.¹⁷ Like most disease registers, local congenital anomaly registers tend to be precariously funded and may be under threat from recent guidelines on confidentiality. In addition, most congenital anomaly registers focus on monitoring the incidence of anomalies rather than attempting long term follow-up of the children concerned. There is clearly a need for this.

4 Monitoring clinical care and adverse outcomes

4.1 The time-honoured way of looking at care which precedes adverse events used in the four confidential enquiries does not involve the use of controls. The Confidential Enquiry into Stillbirths and Deaths in Infancy has recognised its inadequacy and is moving to using controls.¹⁸

4.2 Following a review, NICE is considering the future of the confidential enquiries. The review report recommended extending the approach to a wider range of conditions including primary care and clinical events in the community. It drew attention to the poor quality of routinely collected data and called for 'better patient-focused information systems' in the NHS, pointing out that the lack of controls was often due to 'failure of NHS information systems'.¹⁹

4.3 The need for more unified reporting was also emphasised in the context of adverse event monitoring in the Department of Health report *An organisation with a memory*.²⁰

5 The scope for improvement

5.1 The initiatives under way contain within them a potential for greatly improved monitoring, but the adequacy or otherwise of resources in terms of skills and information technology is a key question. Scotland is ahead of England for a number of reasons. As it gives a higher priority to data collection and use, it invests proportionately more resources to this.

5.2 Another factor in Scotland's favour is the size of its population, which makes these activities more feasible than in England. In the past, there were major information activities at regional health authority level and much was lost when they were abolished. Although public health observatories are a welcome development, the resources devoted to them are tiny in comparison.

5.3 The status and training of staff responsible for administrative and clinical information systems in the NHS is another important issue. Improvements here could well provide greater support to all the key stakeholders who wish to use information for monitoring the activities of the NHS.

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