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Information and intelligence for healthy populations

Important, but maybe just too ambitious

In his report on the resources required to provide high quality health services in Britain, Sir Derek Wanless concluded that “little comprehensive information is collected on the health status of the population,” making it impossible to track, at local level, trends in major risk factors and in patterns of disease. England’s Department of Health has now decided that something must be done to tackle this problem and is seeking views on a proposed new strategy for providing such information, *Informing healthier choices: information and intelligence for healthy populations.*

The government should be congratulated for developing a vision in which real-time, high quality public health data will be delivered via “public health desktops” to a highly trained and integrated public health and local authority work force. It notes correctly that this will be essential for achieving the fully engaged scenario envisaged in Wanless’s first report (about the long term trends affecting the health service in the UK).

The consultation document sets out, in broad terms, how such a vision could be realised. It recognises that creating a fully integrated system will take time and that there is a need to engage with stakeholders, highlighting the central role that will be played by the public health observatories. However, representatives from the much larger number of analysts located in primary care trusts and strategic health authorities are not included in the list of steering group members to implement the strategy, and they need to be.

Major obstacles exist to obtaining consistent, reliable, and accurate data on levels, trends, and patterns of health and healthcare use at local level, some of which the report acknowledges. For example, the census provides denominator data, but up to one million people were missed by the 2001 census. Many of them live in inner cities, and the undercounting combined with high population mobility means that census results from five years ago may be very misleading when applied to current residents in some primary care trusts.

The main source of information on risk factors is the Health Survey for England, typically collecting data on 16 000 adults each year. While the survey’s changing annual focus provides useful in-depth snapshots of different demographic groups and diseases, changes in data collection can make it difficult to assess trends over time. Information on the incidence of many common disorders can be obtained from the Compendium of Clinical and Health Indicators produced by National Centre for Health Outcomes Development (NCHOD), but nearly all these indicators are based on mortality. The General Practice Research Database is another
The palliative role of orthopaedics
Orthopaedic procedures can help terminally ill patients and are underused

Palliative care for patients with cancer is well established and provides important benefits. Orthopaedic interventions in terminal care are, however, underused in the United Kingdom, despite the fact that conditions that are amenable to orthopaedic intervention occur often in the terminal stages of cancer. Though the evidence base for many orthopaedic palliative interventions is not strong, there are no trials, clinical experience and expert consensus opinion suggest that such interventions can ease the valuable source of data, collected from over 3 million patients registered with general practitioners throughout the UK. A collaboration between the Medical Research Council and the General Practice Research Database, now allows for free access to the database for up to 50 approved academically led proposals per year for the next five years; but for others the costs are considerable. This raises wider issues, given the tendency of some government agencies to view data as a tradeable commodity, providing an essential stream of income, rather than a public good.

The new model will involve much more extensive and imaginative use of the vast array of data now being collected within the NHS. However, if public health analysts are to use this information to understand local health patterns, the Department of Health needs to ensure the proposals of Connecting for Health (the NHS’s IT programme) for partly anonymising data for secondary uses will not impede access to complete demographic data, for example to monitor access to services by different population groups. Even if this problem is overcome, five other issues about data collection require resolution, only the first of which is addressed in the consultation document.

This concerns tackling incomplete recording of data, exemplified by data on ethnicity. The second concerns the lack of accessible standardised data from community health services, which are needed to create comparable datasets across the primary and community health sectors. Given the shift towards care outside hospitals this seems to be a key omission. Thirdly, the introduction of new patterns of healthcare delivery, often involving anonymised patients as they move through agencies, is needed that will include elements such as training and those who must collect the data. A multifaceted strategy envisages data sharing between health and local authorities, so practical mechanisms to follow anonymised patients as they move through agencies must be developed. Finally, there is a crucial, but so far neglected, requirement to provide incentives for those who must collect the data. A multifaceted strategy is needed that will include elements such as training and automatic prompts but most of all a clear vision that will convince people that the data they are collecting are actually important.

A major challenge may also arise from the technology itself. The implementation of the national IT programme is cited as a driver for change, yet this exceptionally ambitious programme has suffered major implementation problems, with substantial delays due to problems facing service providers. The United Kingdom’s experience of implementing large scale IT projects is poor and the task is likely to be made more difficult by the current instability confronting the NHS. No other country has ever attempted anything similar, arguably for good reason. Nevertheless, many other aspects of the proposed information and intelligence initiative build on established structures, such as the public health observatories, cancer registries, and the National Institute for Health and Clinical Excellence (NICE), and do not seek to create new organisations.

The proposed strategy is ambitious. It encompasses not only the population health information and intelligence functions undertaken by professional analysts, but also aims to meet the information needs of the general public, who are more likely to want answers to questions about their own health rather than that of a population. If this initiative is given time and sufficient resources, and is set goals that are realistic, it may just work. This would, however, involve a new way of working in all the organisations involved, from Whitehall down.

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Competing interests: MM chairs and RR is a member of the London Health Observatory’s expert advisory committee. SG is also a public health information specialist at Sutton and Merton Primary Care Trust.

2 www.dh.gov.uk/Consultations/LiveConsultations/LiveConsultations-

1 BMJ 2006;332:1227–8

Editorials