

# Access to data in health information systems

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This issue of the *Bulletin* contains a series of articles on the creation of health information systems in developing countries. A broad range of themes is raised — from what information a properly formed health information system ought to collect, to rationalizing the collection of information across agencies or institutions, and a consideration of the costs, benefits and potential uses of information that is amassed.

The issue of ensuring access to data in developing countries is striking in both similarity to and differences from the situation in developed countries. The main difference is that in developing countries access is limited by a sheer lack of data: concerns and priorities of health information systems are often about collecting information that does not yet exist. Efforts focus on putting basic vital event registries in place, or in making better use of those registries by permitting relatively straightforward linkages of census and death records so that basic demographic measures such as life expectancy can be produced (see AbouZahr & Boerma (pp. 578–583) and Bambas Nolen et al. (597–603)).

Similarities lie in the fragmented approaches that are often undertaken to develop new data collections as well as in the lack of explicit attention at the outset to processes that would enable resourceful use of data. The primary reason for collection might be programme evaluation or the production of statistics that can be compared across countries, for example. Attention to future data access and use issues prior to data collection may help create the capacity to conduct comparisons across countries, to monitor changes over time, and to use the data in combination with other data holdings.

In developed countries, such as Canada, the lack of explicit consideration of future uses of data in the planning stages of collection has resulted in a fragmented world of data where some

decision-makers and researchers are able to find and use information and others are not. The data exist, but they are not easily accessible. Limited access diminishes their value and means that the sunk costs of data collection are just that — sunk (1). The lack of foresight in creating data access policies poses a problem that now demands a solution.

In developing countries, where investments in health information systems are relatively new, there are opportunities to incorporate access policies and processes at the start. If appropriate responses to legitimate demands for access to data can be “baked in rather than painted on” (2), there is greater potential for wider use and benefit from data collection activities. Below is a brief list of data access questions that ought to be considered in the early stages of health information system development.

- *Who owns the data?* Does the data collector, the local or national government or the community ultimately “own” the data that are gathered from the population? The issue of control has been a recurring problem, where local groups feel alienated from decisions about data planning and data collection (see AbouZahr & Boerma, pp.578– 583). What can be done to avoid this conflict? The appropriate locus of control may vary from data set to data set, but ownership issues should be solved prior to data collection.
- *Who is responsible for the data?* In many cases, collected data will have identifiers such as names and birth dates. Are there local restrictions on how or under what circumstances such data are collected? On how they are stored? On how long they can be kept? Is there a consent process? Data collection will always be more cost-effective if the data can serve more than one purpose, but such multipurpose efforts have to fit with local rules and customs.

- *For what purposes will the data be used?* When data are collected there is clearly a primary purpose in mind, such as programme planning and evaluation, but what about beyond that? Are there subsequent uses that can be anticipated? How much latitude should there be for previously unanticipated uses?
- *If the data will (or may) be used, what controls will be put in place to govern that use?* Do individuals who are represented in the database need to be apprised of any subsequent use of data? Does the community require a say in what happens with the data? Does a local representative need to be involved in any such use?

These may seem far-fetched concerns when countries or districts are only in the planning phases of data collection and development. Based on experience in developed countries, however, this is the perfect time for such considerations. Ultimately, the public will benefit from this forethought, especially if good quality, useful data sets are developed and then made available for subsequent analyses that can provide guidance to improve health and health care. ■

1. Black C, McGrail KM, Fooks C, Baranek P, Maslove L. *Data, data everywhere: improving access to population health and health services research data in Canada*. Vancouver: Centre for Health Services and Policy Research; 2005.
2. Patilla JC. *Security must be baked in, not painted on*. eWeek.com, 6 August 2001. Available from: <http://www.eweek.com/article2/0,1759,465346,00.asp>

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