

Book reviews

Health Data in the Information Age: Use, Disclosure and Privacy

Edited by Molla S Donaldson and Kathleen N Lohr, Washington DC, National Academy Press, 1994, 257 pages, £32.95.

Health Data in the Information Age is the report of a multidisciplinary committee of the US Institute of Medicine, composed largely of clinical directors and information technology experts. It examines the development of technology which has allowed data to be aggregated into vast sets, and considers both the potential for good and harm arising from such informatic power.

The report should be read with two provisos in mind. First, the Health Database Organisations (HDOs) which it considers, are thought of as secondary records, distinct from an individual patient's medical record. This distinction allows the editors more easily to dismiss concerns over the unauthorised viewing of confidential health information, on the grounds that the databases will largely contain information that cannot be identified with any one patient. Concerns relating to prurient hackers, journalists and other undesirables breaking into the system(s) are thus alleviated. This distinction also means that the law relating to primary medical records (for instance, with regard to compulsory disclosure of notifiable diseases or gunshot wounds) would not apply to the HDOs, prompting the committee to recommend specific federal legislation.

The second limitation on the report is one that it itself acknowledges, although it sees it as a strength: it is that databases of the sort envisaged and discussed remain, as yet, on the informational drawing board. This

gap between the *status quo* and the brave new world of the database means that the report is forced to project somewhat into the future – “eventually”, “perhaps”, and “one day” occur repeatedly. The enthusiast would argue that this represents a commendable attempt to shape technology before we are shaped by it, and would not be unduly concerned at the gap between vision and practice in health informatics. The more reserved sceptic might be inclined to wait to see what in fact was on the technological menu before he or she placed an order.

Perhaps it is this concern that the report should be as much a vision of the future as a consideration of the present that forces the editors to adopt a relentlessly technical style. The tone of the report is no clearer than might be expected from a sixteen-strong committee, even one composed of computer experts: its thirty pages of definitions and eighty-odd acronyms scarcely persuade the ordinary intelligent reader to linger, although it has a more useful twenty-five page summary.

It is to the report's credit that it recognises that the problems associated with health data collection and release go beyond standard issues of confidentiality and the privacy of celebrities. The editors, for instance, canvas concerns surrounding the amassing of performance data from individual units and extrapolation from such data, warning that simple aggregation of figures will not necessarily produce a useful ordinal ranking.

The report's conclusions are perhaps not entirely surprising, ranging from the frankly banal (that database managers ensure that their data are reasonably accurate) to recommendations derived from existing law and views on the confidentiality of medical records. This linkage between current practice relating to paper records and future electronic data lends support to

the editors' views that the ethical and legal concerns surrounding data collection are the same whether these data are stored in a filing cabinet or on a networked computer. If this is so, then the report's desire for new federal legislation to regulate collection and dissemination of health data in electronic format calls into question the present law's adequacy to protect even paper records.

The report is interesting as an example of how the possibilities and challenges of the much-vaunted information age are being addressed in a medical setting. Although its treatment of its concerns is hardly new, its account of the developing landscape of health informatics is of some value. There is an extensive bibliography.

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Ethics for Everyone – a Practical Guide to Interdisciplinary Biomedical Ethics Education

L C Grafius, Chicago, American Hospital Publishing Inc, 1995, 223 pages, US \$49.pb.

The author of this book has set out to write an introduction to education in biomedical ethics (for which, depending on your location and preferred jargon, read health care ethics, bioethics or medical ethics); and not only to education but to interdisciplinary education in these areas. For this reason we might have expected a book aimed amongst other things, at convincing teachers of health care ethics that they should teach ethics in an interdisciplinary context. As an intro-