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A New Voice in Science. Patient participation in decision-making on biomedical research

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A New Voice in Science. Patient participation in decision-making on biomedical research

Abstract

Book review

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For this reader it was the authors' analysis of these patterns of information-seeking that provided the most interesting material. They believe that existing models for the way patients use information are misleading and simplistic. In numerous studies on the subject, health information is seen as a right, a commodity or a form of medical intervention. They argue that it should be seen as a tool because from the perspective of the patients they interviewed, what mattered was not simply to have information, but to be able to do things with it. It follows that patients cannot just be divided into the informed and the uninformed. Patients use information in different ways, including choosing not to be informed on some occasions.

Similarly, they argue that patients will use a variety of techniques to navigate their way through information. Although anything that appears to be too complex will be off-putting and therefore not used, the patients in the pilot studies tended to adapt familiar ways of seeking information to the *mihealth* system. Research studies often distinguish between different formats, but these distinctions were less important to the patients in this study. Indeed information that could not be readily transformed by being printed out, audio-recorded, written down or turned into a question, was generally regarded as useless. The report identifies horizontal and vertical information seeking behaviours. Patients wanted information about what will happen next, but they also wanted the option to delve deeper into any particular aspect of their disease.

The authors see the clinical setting as an 'information hub' but recognize that what doctors think patients should know and what patients actually want to know can be quite different. They therefore conclude that a successful information resource should help patients work with their doctors, but also stand back and assess the treatment they receive.

Having provided an insight into the complexities of the way patients search for and use information, the second part of the report applies this knowledge to *mihealth* to evaluate how well it responded. The authors acknowledge that recruitment to the study was slow and offer

possible reasons for this. However, they found that for those patients who did participate, the system performed extremely well. The *MiInformation* function was the most popular, allowing patients to search for as much or as little information as they wanted. The less successful elements were those that enabled patients to personalize information, for example, *MiDiary* and *MiMoodstates*. They argue that this could be because the core function, *MiInformation*, operated so well, patients did not feel the need to go beyond this.

The authors make a small number of suggestions for its further development, but essentially conclude that *mihealth's* flexible and multi-functional design proved very successful in meeting the needs of patients with a range of skills and competencies. They found that the non-patronizing, user-centred design of *mihealth* works because although it depends on very new technology, it builds upon patients' existing patterns of information use. In providing information that is relevant and enabling patients to manage that information on their own terms, it supports shared decision making in a real and meaningful way.

This is a thoughtful and well-written report which is strongly recommended for anyone involved in the development of patient information services.

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A New Voice in Science. Patient participation in decision-making on biomedical research

By Francisca Caron-Flinterman, 2005

ISBN 978 90 9019996 2, 192 pp. Free copies can be requested from the author directly at: francisca.caron.flinterman@falw.vu.nl

This book sits at the intersection between science and technology studies and the emerging field of public participation in health decision-making.

The focus, as the title suggests, is on the involvement of patients in decision-making about biomedical research. The starting point is the simple observation that patients are playing an increasing role in decision-making in a wide range of areas related to health – including health services research, health technology assessment, clinical care and priority setting for health resource allocation – but they appear to have surprisingly little input into biomedical research. The book sets out to explain why this is so and to explore the strategies that might be adopted to enhance patient involvement. The latter part of the book develops, implements and evaluates a process for integrating patients into decision-making about biomedical research.

A New Voice in Science clearly began life as a PhD thesis. This is both a strength and a weakness. The early chapters on the book provide concise reviews of literature across the range of disciplines that are relevant to the topic: there is a description of the nature of biomedical decision-making networks; arguments for and against patient participation in decision-making (more of the former than the latter); accounts of obstacles to patient participation and strategies to manage these; and some very clear writing on the epistemology of patient knowledge and experience. As someone who had read rather more narrowly within this field, I found the breadth of disciplines covered and the clarity of writing about each most helpful. However, there are moments when the book's origin in a PhD thesis becomes an impediment to graceful and efficient writing. There is some repetition, an excessive amount of classification, and a tendency to overstate the gaps that the book fills. Some chapters were also published initially as journal articles, and these chapters still read, to some extent, as stand-alone pieces. Mostly, Caron-Flinterman succeeds in crafting a book out of a thesis, and the occasional lapses into 'PhD-ese' are understandable.

For me the best parts of the book are the final chapters, in which Caron-Flinterman describes

and evaluates a 'social experiment': integrating patient views on priorities for asthma and chronic obstructive airways disease research into a research agenda. In the first part of the experiment, patients' priorities for research were explored using a mix of qualitative and quantitative methods. It was clear that patients were capable of participating in a research agenda setting exercise. In addition, patients' highest priorities turned out to match those of the relevant national research funding agency, and they placed a higher priority on biomedical research than on research on health-care, social or political issues. Somewhat surprisingly, this finding is accepted without asking too many questions about why it might have occurred. The second part of the experiment extended the consultation process to researchers and health professionals, and used this as the basis for collaboration and prioritization stages. There is a detailed evaluation of the experiment, which finds that the participation strategy outlined above provides an adequate mechanism for involving patients in research agenda setting.

A New Voice in Science is certainly worth reading on at least two counts. First, for the reader new to writing about patient participation in decision-making, Caron-Flinterman provides a comprehensive account of the background to and rationale for that participation. Secondly, the chapters on the social experiment provide a description of evaluation of a complex programme that any research student would benefit from reading. My only criticism is that *A New Voice in Science* lacks the sharply critical edge of other writing in science and technology studies, and perhaps, all things considered, this is not such a fault after all.

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