Chapter IX
Involving Patients and the Public in E–Health Research

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ABSTRACT

This chapter deals with the principles and practice of patient and public involvement in e-health research, and discusses some of the issues raised. In the first part of this chapter, we discuss the problems of defining an "e-health consumer," and discuss why, how and when to involve consumers in e-health research. We also set out principles to guide effective consumer involvement, and the benefits that this can bring in the e-health arena. In the second part of this chapter, we describe how consumers were successfully involved, through a variety of methods, in the development and evaluation of an Internet-based intervention to aid diabetes self-management. Patient and public involvement in research is not the same as undertaking research on patients or the public. It is about understanding, incorporating and benefiting from the relevant consumer perspective, at various levels, throughout the stages of a project.

INTRODUCTION

Consumer involvement in research is not the same as undertaking research on consumers. It is about understanding and incorporating the consumer perspective into the project, often from the very initial stages. Effective consumer involvement can bring many benefits to e-health research projects—from identifying the most relevant outcome measures, to aiding recruitment of research participants, to assisting the dissemination of findings. We are indebted to staff at the UK consumer involvement charity INVOLVE for their assistance with our consumer involvement strategy at Warwick Medical School, and for the materials on consumer involvement available at www.invo.org.uk.

The achievement of meaningful and useful involvement of consumers in research is a challenge for all health services researchers. It is of particular interest to those working in the field of e-health for several specific reasons which themselves create further challenges. First, e-health is a new field with an emerging research agenda, and is therefore well placed to benefit from the different insights that consumers can bring. But equally, as a new area do consumers have sufficient knowledge to give informed comment? Second, while it is relatively straightforward to identify (for example) people with diabetes to help with diabetes research, e-health consumers do not in general define themselves as such. This creates challenges of definition, and challenges for recruiting consumers. Third, e-health researchers will naturally look to methods of e-involvement to achieve consumer participation in research, but these have their own problems. Not least among these is the exclusion of certain consumers who may not be e-health literate (Norman & Skinner, 2006), but who may still have important contributions to make.

In this chapter, we will establish the principles and conceptual basis for involving patients and the public in the development and evaluation of e-health applications. We will also review and discuss current approaches to consumer involvement in the development of e-health applications. Finally, we will demonstrate how consumers were successfully involved in the development and evaluation of an Internet-based intervention to aid diabetes self-management.

BACKGROUND

The terminology in this area can be problematic (Herxheimer & Goodare, 1999). Health consumers have been defined, in a rather all encompassing fashion, as "patients, past patients, prospective patients, long-term users of health services, relatives caring for patients or users, and people who speak for these primary consumers through local and national support and activist groups, community organizations such as community health councils, local and national coalitions of such groups, and international networks" (Williamson, 2001, p. 661). None of the alternative terms used to describe people who interact with health services and whose views we wish to capture (consumers, users, patients, clients, lay individuals, and so on) is value-free (Coulter, 2002). These terms are often

Box 1. Ten reasons for involving consumers in e-health research (Incorporting findings from Hanley et al., 2004)

1. To ensure that research topics which are relevant to real people get priority
2. To bring a different perspective to help shape an emerging field of research
3. To capture first hand experience of a health condition
4. To improve methods
5. To improve results
6. To facilitate the adoption of research findings
7. To involve the people whose taxes fund public research programmes
8. To involve the people who will be most affected by the research findings
9. To build capacity of consumers with e-health research skills
10. To empower the consumers of e-health services

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