

Chapter XIII

Assessing a Patient–Centered E–Health Approach to Chronic Disease Self–Management

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ABSTRACT

This chapter explores how in developing patient-centred e-health systems it is possible to accommodate heterogeneous characteristics of end-users and their diverse health and care contexts. It concurs with conventional sociotechnical design paradigms that argue systems must be easy to use, fulfill a perceived need, and present a clear value proposition to ensure successful adoption and utilisation by patients. The chapter also highlights the need for awareness of a number of key challenges relating to emerging discourses on ‘empowering patients’ and ‘e-health’. The implications of these challenges for the development of a truly patient-centred e-health approach are explored in a detailed case study. This chapter contributes to research focused on supporting patients to become genuine co-participants in their own care, health and well-being. However, it also acknowledges that part of the challenge of achieving this goal requires a focus on assisting clinicians to learn to respond to this shift in the autonomy of decision-making.

BACKGROUND

Health reform has been a major item on political and policy agendas across the developed world. Alongside changes to health system funding arrangements, medical insurances and the legal and regulatory environments, e-health initiatives have been identified as major drivers for stimulating the changes necessary to address the crisis. By opening up opportunities for increased information access, cost effectiveness, improved information delivery, update and evaluation the economic case for more information and communication technology (ICT) is strong. However, this deployment also raises a number of sociotechnical, clinical, and legal challenges that have become increasingly evident as the implementations of more sophisticated ICT solutions have met with mixed success or failed to generate their forecast benefits. E-health innovations do have huge potential to support a “better connected health system” that is more efficient, safer, and knowledge-based and provides universal, accessible, and affordable care. However, many approaches to e-health continue to downplay high levels of complexity and uncertainty that exist in the delivery of healthcare services and make problematic assumptions about how ICTs will benefit patients, health professionals, and the healthcare system as a whole (Cummings & Turner, 2007).

The growing crisis in healthcare delivery is also at least partly attributable to the increasing incidence of chronic illness and complex medical conditions associated with the rapidly ageing populations of most ‘first world’ countries. The focus on chronic illness is directly related to the fact that up to 75% of patients presenting for healthcare have chronic conditions (Epping-Jordan, Bengoa, Kavar, & Sabate, 2001; Fries, Friday, Gira, Cooper, England, Graves, Sokolov, & Wright, 1993). There have been numerous responses to chronic illness, including one set of approaches that emphasize the importance of enfranchising and empowering the patients and/or

their carers to become co-participants in their own care. At the most basic level, these approaches are premised on assumptions that patients are both able and willing to participate, that their involvement will improve disease treatment, management, and education, and the net result will be positive results in terms of health outcomes. To date, the wide range of methodologies and assessment procedures used by those implementing these approaches has made comparisons difficult. Although most evaluations have reported some benefits, it is evident that considerable complexity and uncertainty remains regarding how best to support self-management of chronic illness (Warsi, Wang, LaValley, & Avorn, 2004).

INTRODUCTION

This chapter examines a number of key challenges related to the emerging discourses on “empowering patients” and “e-health.” The implications of these challenges are explored in a detailed case study. The case study presented in the second part of this book chapter highlights the inherent challenges of moving towards a patient-centred model of healthcare. The case study focuses on a controlled trial that aims to assist people with chronic respiratory conditions, including chronic obstructive pulmonary disease (COPD) and cystic fibrosis (CF), to achieve increased levels of self-efficacy for self-management through interactions with case mentors (community health nurses), and the adoption and use of Web and mobile information systems.

This chapter promotes a patient-centred e-health approach. It is argued that benefits from such an approach can only be realised if systems are specifically designed and implemented on the basis of a detailed understanding of end-users, their needs and complex interactions with one another, the health system, and the wider environment. Without such a holistic approach, there is a concern that the existing inequities of access

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