ABSTRACT

Given the potential of health internet-registers, this study examined how such registers can be made more effective and efficient. This involved investigating the actual barriers to usage experienced by those for whom such registers are established to help. To elicit responses regarding the opinions, views, and experiences of participants, concerning their various reasons for non-progression or non-completion of the pilot UK MS Register, a list of ten potential key areas of difficulty, in the form of short statements, was e-mailed to participants. A content analysis revealed that there were four main areas of concern that could represent potential barriers for health internet-registers, in general, and that need to be considered when establishing, designing, and developing such registers: technical aspects of using the internet; computer literacy and ability, encompassing website design, clarity, and user-friendliness; symptom mismatches with register content; and condition-specific effects and impacts as barriers to internet-register use.

Keywords: Health Informatics, Health Internet-Register, Long-Term and Chronic Condition, Multiple Sclerosis (MS), Qualitative Content Analysis
INTRODUCTION

The internet is playing an increasing role in medicine and health (Conrad & Stults, 2010; Riegelman & Persily, 2001). One manifestation of this development is the emergence of health internet-registers, the uses and impacts of which have been described and reviewed in a number of articles (see Drolet & Johnson, 2008; van der Veer, de Keizer, Ravelli, Tenkink, & Jager, 2010). Such web-based registers have been developed and utilized for various different diseases, conditions, and disorders, such as: Diabetes (e.g., McKay, King, Eakin, Seeley, & Glasgow, 2001), Stroke (e.g., Asplund, Asberg, Norrvings, Stegmayr, Terent, & Wester, 2003), and Autism Spectrum Disorders (e.g., Daniels, Rosenberg, Anderson, Law, Marvin, & Law, 2012). In Multiple Sclerosis (MS), there are several such internet-registers (Hurwitz, 2011); for example, the pilot UK MS Register (Ford, Jones, Middleton, Lockhart-Jones, Maramba, Noble, Osborne, & Lyons, 2012; Osborne, Noble, Lockhart, Middleton, Thompson, Maramba, Jones, & Ford, 2012). Such registers have potential to reach great numbers of people (see Epstein & Klinkenberg, 2002), and act as repositories for collecting wide-ranging data sets that can be updated regularly (e.g., Evans & Mathur, 2005), generating an extremely useful clinical and research tool (see Daniels et al., 2012; van der Veer et al., 2010). Given their potential, it is vital to understand how these registers can be made as effective and efficient as possible.

There are recognized limitations to using the internet as a data-gathering vehicle for medicine and health. The internet is not accessible to all, leading to the ‘digital divide’ (Brodie, Flournoy, Altman, Blendon, Benson, & Rosenbaum, 2000; Watson, Bell, Kvedar, & Grant, 2008). For instance, some older people do not have access to the internet (over 40% of people older than 65 have never used the internet; Williams, 2011), nor, if they do have internet access, do they generally use it as regularly as younger people. However, this particular aspect of the ‘digital divide’ may be reducing over time (in 2000, 91% of those over 65 had not used the internet; ONS, 2000). For MS, this may not represent a major limitation, as, unlike some other chronic conditions (e.g., stroke), MS is not a condition that affects older people disproportionately (the average age of clinical onset is 30-33, and the greatest prevalence is 30-60; Acheson, 1977).

Such limitations aside, the internet community represents a large potential population that can be reached easily and quickly. However, even within the population accessible through internet-registers, there are still barriers to the usability and usefulness of such data-collating methods. Internet-registers may be limited by the quality of the information that they collect, for instance in the range and quality of the questionnaires and measures deployed (Ebers, 2010). Another potential barrier to registers’ use and quality is their engagement of clinicians and patients (Carr, Howells, Chang, Hirji, & English, 2009; Powell, 2004). Therefore, it is important to identify barriers to use to eradicate as many obstacles as possible, and develop registers that are optimally useful and encourage respondents to return, providing continuing longitudinal data. The focus here will be on barriers, identified by people with MS, to using an internet-register.

There is a growing literature on barriers to use of the internet for medicine and health; mainly concerning obtaining information on various conditions (Skinner, Biscope, & Poland, 2003). This has identified a number of issues, among people who use the internet regularly, that may prevent them from using it for medicine and health (Porter & Donthu, 2006; Skinner et al., 2003), many using populations drawn from the USA (Lobert, Zierler, Herbaugh, Shinstrom, Stolyar, Kim, & Kim, 2006; Skinner et al., 2003). These issues include confidence in using the internet (Watson et al., 2008), trust in a website (Porter & Donthu, 2006; Skinner et al., 2003; Watson et al., 2008), accessibility and advertising of a website (Lobert et al., 2006), and the website’s functionality (Skinner et al., 2003). These studies have employed a wide range of conditions (e.g., diabetes, Watson et al., 2008; sexually transmitted diseases, Skinner.
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