Sources of Discovery, Reasons for Registration, and Expectations of an Internet-Based Register for Multiple Sclerosis: Visualisations and Explorations of Word Uses and Contexts

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ABSTRACT

Internet-registers are having an increasing role in healthcare informatics. Understanding the motivations and expectations of people choosing to use such registers is important, and these aspects were investigated regarding people with MS who registered on the UK MS Register. An objective was to explore relationships between these factors and the source from which participants first learned about this Register; as this is relevant to how registers are publicised. The responses from a large number of participants (N = 2,675) to questions about the source by which they discovered the Register, why they registered, and how they thought it should be used, were qualitatively analysed using a ‘word cloud’ technique and traditional content analysis strategy to provide a more detailed analysis. The significant trends that emerged from these analyses were the importance to the participants of: studying MS; raising awareness about MS; improving and developing services and policies regarding MS; assisting others with MS; the Register as a resource for people with, and affected by, MS; the Register as an aid to themselves; and it being an open resource for all professionals and government bodies.

Keywords: Content Analysis, Discovery Sources, Expectations, Healthcare Informatics, Internet-Registers, Multiple Sclerosis, Qualitative Analysis, Registration Motivations, Word Cloud

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INTRODUCTION

The development of internet-based registers for health and medical purposes is becoming more frequent (Conrad & Stults, 2010; Hurwitz, 2011), and the UK MS Register is one such development, which is the first UK-wide register of its kind (Ford, Jones, Maramba, Middleton, Osborne, Noble et al., n.d.). Developments of this sort can act to collate and link wide sets of data across a large geographical area, nationally or internationally, and can be invaluable resources for research purposes, and for service provision assessment, planning, and future implementation (Ford et al., n.d.; Hurwitz, 2011).

Given the growth in internet-based health registers, and their potential value, it is important to ensure that such internet-based registers perform as effectively and efficiently as possible, and, to this end, there are numerous issues to be considered. For instance, it is important to ensure that the scientific and research rationales are fulfilled, and that the data collected are reliable, valid, and useable (Ebers, 2010; Osborne, Noble, Maramba, Jones, Middleton, Lyons, & Ford, n.d.), hence, the measures and questionnaires selected must be appropriate and correct for the purposes for which they are to be employed (e.g., Goldman, Motl, & Rudick, 2010; Osborne et al., n.d.). Also, the technical performance of these registers, as well as their designs and web layouts, are paramount to their success (e.g., Lober, Zierler, Herbaugh, Shinstrom, Stolyar, Kim, & Kim, 2006; Skinner, Biscope, & Poland, 2003). These, and related, issues have been examined when investigating the success, and the barriers to use, of such internet-based registers in the context of health and medicine in general (Porter & Donthu, 2006; Skinner et al., 2003), and MS in particular (Atreja, Mehta, Miller, Moore, Nichols, Miller, & Harris, 2005; Osborne, Noble, Maramba, Middleton, Thompson, Lockhart, & Ford, n.d.).

Two aspects that have received less attention are those of the motivations and expectations of those individuals for whom such internet-based registers are developed. As such registers often rely very heavily on self-reports and/or patient reported outcome measures (e.g., Miller & Allen, 2010), it is essential to explore the motivations, expectations, and presuppositions of the target population concerning such registers. It is well known that expectations influence perceptions and behaviour, in general (Ajzen, 1991; Cella, Taylor, & Reed, 2007), and health-related behaviours in particular (e.g., Fishbein & Yzer, 2003), and these may colour the way in which questions on internet-based registers are viewed (Osborne et al., n.d.). If expectations do not match with the presented product, it is possible that respondents will cease to use such health registers and desist from supplying information to them. Although this effect has not been investigated in relation to the use of health registers, there is evidence that unfulfilled expectations lead to higher attrition levels in attending health-related treatment and intervention sessions (e.g., Librizzi, 2006). If such an effect did occur in the context of a health register, it would subsequently damage the potential utility and reliability of such resources. Given this, the current paper examines the expectations, and motivations, of people with MS regarding the UK MS Register.

A successful launch and the subsequent ongoing effectiveness of an internet-based register necessitate widespread advertising and publicity (Lober et al., 2006). However, the various sources through which people can discover the existence of an internet-based register may possibly be associated with different motivations, expectations, and related assumptions about that register. There is much evidence, from the Psychology and Marketing literature, that publicity, and the form that advertising takes, impacts on people’s expectations (e.g., Hope, Memon, & McGeorge, 2004; Jaeger & MacFie, 2001). However, there is little evidence concerning whether this happens in relation to the publicity concerning internet-based health registers. The current paper also examines this possibility, and aims to shed light on whether there are any nuances of how people view a register associated with different advertising and publicity sources.
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