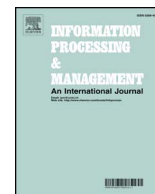


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## Anticipating ageing: Older adults reading their medical records

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### ABSTRACT

In spite of the general interest in health information behaviour, there is little earlier research on how older adults, who are still active in working life but approaching retirement, differ from other age groups. A survey with Swedish patients who had ordered and read their medical record was conducted to map the preferences and motivations of older adults (born 1946–1960) ordering a copy of their medical record, and using medical records based e-health and information services in the future. The results do not indicate an obvious linear relationship between age and motivation to use online health information but show several differences between the age groups. Older adults were less interested in communication with their medical doctor by e-mail. Yet, they had searched health information in the Internet during the last week more likely than young. They were more inclined to read medical record to get an overview of their health than young, but less confident that they understood most of the content or turn to their family and friends to seek help than the elderly. When compared to younger adults and elderly people, older adults are the least confident and least motivated to use online health information. It is suggested that older adulthood can be seen as a transitory stage of life when the need of health information increases and engagement with health changes. The results agree with prior research on the potential usefulness of (online) medical records as a way to inform citizens. However, specific provision strategies may be necessary to match the needs and motivations of different age groups.

### 1. Introduction

The population is ageing rapidly in many developed countries. People are encouraged and required to engage (Mockford, Staniszevska, Griffiths, & Herron-Marx, 2012) and take a more active role in managing their own health. Participating in decision-making related to health and medical care has been identified as a potential remedy to the challenges faced by healthcare systems around the world (Hibbard et al., 2013; Nease, Frazee, Zarin, & Miller, 2013). A central premise for being informed and able to make decisions regarding health and healthcare is to have access to health information and medical documentation relating to one's own current condition, previous and planned treatments, and visits to healthcare providers (Clarke et al., 2016; de Lusignan et al., 2014). This can be seen as part of personal health information management (PHIM) (e.g., Ancker et al., 2015; Lustria et al., 2011, Pratt, Unruh, Civan, & Skeels, 2006).

An adequate understanding of the health information behaviour of older citizens is crucial for development of services and

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systems for health information seeking and retrieval (Sanchiz et al., 2017), and providing such information for this group in a manner that would encourage and help them to become better informed and to take more responsibility for their healthcare. Understanding the actual health information behaviour and its premises is pivotal for avoiding idealised assumptions of the over-rationality of patients and categorising their behaviours as bad (Johnson, 2014). With older citizens, this is especially vital in the group of older adults who are approaching old age but are still active in working life, and on average, have many years of life ahead. In comparison to old elderly, older adults have been suggested to be more knowledgeable of recently introduced technologies and with them, the use of e-health technologies and health behaviour change has been argued to have a more significant impact than with elderly individuals with shorter expected remaining life-time (Nikou, 2015). In spite of the growing corpus of research on older citizens, their health (WHO, 2015), health information literacy (Enwald et al., 2017; Eriksson-Backa, 2013; Eriksson-Backa & Ek, 2015; Yates et al., 2012), and health information behaviour (Eriksson-Backa, 2011; Medlock et al., 2015), there are still relatively few studies that investigate specific characteristics of this group and how older patients differ from other age groups (Huvila et al., 2016). Furthermore, as the typical focus on ageing suggests, much of the earlier research has treated the elderly population as a relatively homogenous group although there are major differences between older adults who are still active in working life, the ones who have retired only recently, and the age group of the oldest old (Asla & Williamson, 2015). In addition, none of these groups are homogenous, either.

This article reports on how older adults (born 1946–60) differ from younger or older individuals concerning their health information behaviour and their preferences regarding reading of medical documentation, and use of online e-health services. The analysis is based on the results of a survey of individuals (N = 354) who have ordered a copy of their medical records from a regional healthcare authority in a Swedish county.

## 2. Background

There is a lot of research relating to health information and health information behaviour (Case & Given, 2016), health information literacy (Suri, Chang, Majid, & Foo, 2014), searching and retrieval of health information (Zhang, 2014), and different aspects of medical records from preservation (e.g. Dong, 2015; Stanberry, 2011) to how they are used by patients (e.g. Huvila et al., 2016; McNamara et al., 2015) and healthcare professionals (e.g. Grünloh, Cajander, & Myreteg, 2016; Shaw, 2013), both in information science and related fields. Instead of attempting to review the entire field, the following section reviews the issues of health information, e-health, and medical records related research that are pertinent to this study: patient engagement, information access, access to medical record information, and ageing with a focus on older adults (i.e. patients) and healthcare perspectives to providing access to information.

### 2.1. Patient engagement and access to information

Engaging patients is internationally recognized as a key factor in improving health service delivery and quality (Mockford et al., 2012) and is found to have a positive impact on the development and evaluation of purposeful health information technologies (Darking et al., 2014) and health outcomes and also, albeit to a somewhat lesser degree, healthcare costs (Hibbard & Greene, 2013). In general, patient engagement refers to the level of patients' activation: an engaged patient as "an active agent in the management of his/her own health" (Hibbard, Stockard, Mahoney, & Tusler, 2004). Gruman, Rovner, French, Jeffress, Sofaer, and Shaller (2010) define patient engagement as the actions individuals may enact to participate knowledgeably and actively in their own healthcare to realize its full benefit. Part of the patient engagement movement is providing patients access to their own medical records and other health related information. Today, patients have to take care and be aware of many types of personal health information. This relates to personal health information management (PHIM) (e.g., Ancker et al., 2015; Hartzler et al., 2017; Lustria et al., 2011) where an engaged patient may become more aware of his symptoms, diagnosis and treatments and use healthcare more efficiently. The findings of Hoerbst, Kohl, Knaup, and Ammenwerth (2010) in a study of Austrian and German patients suggest that in general population, patients have interest in PHIM. Making patients co-producers of their health can enhance their satisfaction with the healthcare system as well as their responsibility in both care and prevention and thus improve clinical outcomes and reduce health delivery costs (Graffigna, Barello, Riva, & Bosio, 2014).

There has for long been a debate about the informed patient and a 'partnership' between practitioners and patients as well as a notion of 'informed choice'. It is thought that informed patients are better at assessing risks and benefits of treatments (e.g., Henwood et al., 2003; Karnam & Raghavendra, 2017; McColl-Kennedy et al., 2017). Engaged and informed patients are expected to take more responsibility for their own health (Graffigna et al., 2014; Henwood et al., 2003) but this is not only achieved by being provided information passively, also one's own activity including seeking of information is required (Lloyd, Bonner, & Dawson-Rose, 2014). Information about health is, however, often available from different sources and is presented from different angles, and it has been said that in the complex and often confusing situations where it is obtained, a person needs to master the information (Eriksson-Backa, Ek, Niemelä, & Huotari, 2012). In order to become informed, certain competencies and skills related to information itself and use of sources, also called information literacy, are relevant, and being uninterested in, for example, validity issues can act as a "constraint on the emergence and enactment of the informed patient identity" (Henwood et al., 2003, 604).

### 2.2. Ageing and access to health information

It has been found that people's relationship with health information may become more intense with increased age (Niemelä, 2006, 121) and deteriorating health may raise specific health information needs (Alpi & Bibbel, 2004). A recent study on the web searching

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