

Self-Managed Access to Personalized Healthcare through Automated Generation of Tailored Health Educational Materials from Electronic Health Records

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Abstract

The evolution in health care to greater support for self-managed care is escalating the demand for e-health systems in which patients can access their personal health information in order to ultimately partner with providers in the management of their health and wellness care. At present, unfortunately, patients are seldom able to easily access their own health information so, as a result, it is often difficult for patients to enter into a dialogue with their healthcare providers about treatment and other options. One truism seems to be constantly ignored: it is not possible for patients to actively manage their health without the requisite information. Health information should be made available through ‘any time, anywhere’ delivery: outside the physician’s office or hospital, in the home or other personal setting, on a variety of multimedia information devices. We believe that personalization of health information will be a key element in effective self-managed healthcare.

The Need for Self-Managed Care in e-Health

The evolution in healthcare to greater support for self-managed care—for example, in-home access to diagnostic and information services—is escalating the demand for e-health systems in which patients can access their personal health information in order to ultimately partner with providers in the management of their health and wellness care. While research demonstrating the benefits to patients of accessing their own health record has been mixed at best, we believe the lack of clear success in this area is a result of factors such as poor data management, inadequate interfaces, and awkward, impersonal information structuring. The failure to address self-managed health care, that is, comes from the inadequacies of the information systems, not from a lack of need. Other researchers, in health informatics and in interaction design, are addressing some of these inadequacies. But very little work is being done on what we consider the most important factor: tailoring the information to individual needs, experiences, and communication style. It is not just that people need access to their own health information. They need it in formats they can understand and interpret properly.

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We believe that effective self-managed healthcare should involve the personalization of health information: with individually tailored information, the patient would be better-educated about their specific condition and better able to enter into a dialogue with their physician to make informed decisions. With tailored messages, the patient is likely to be more-engaged, so that they read, comprehend, and act upon the information.

Self-Managed Care and the Electronic Health Record

Despite the strong case for self-managed care, however, patients don’t have sufficient access to their own health information. The primary reason is that the healthcare field has lagged behind other industries in moving to electronic data capture and retrieval. This is due to many reasons, not the least of which is the dollar investment required and the sheer desire to establish and achieve strategic objectives (see (Leonard 2000) for a more detailed presentation and discussion). Our belief is that chronically ill patients, those with a lifelong illness or a disease that has long-term implications, are the best choice for “early adopters” who will benefit most from self-managed care and access to patient-centric electronic health records (EHRs). On the personal side, this is the group that is faced with daily concerns about their current health status, has much higher healthcare services utilization, and is most likely to demand and search for information related to their health. Because of this group’s frequent interaction with the healthcare system, it is also likely to be the one most frustrated with current healthcare delivery, and therefore with the most to gain from self-managed care. On the healthcare business side, research in a number of economically developed countries has estimated that about 40% of the general population has a chronic condition, accounting for nearly two-thirds of all medical expenditures in these countries (Shine 2002). If these patients were to become more enabled and empowered through access to their own health information, this would have a dramatic effect on reducing overall healthcare costs while providing more accessible and effective care.

The focus on chronic disease management must begin now and should incorporate self-management e-health tools. Prototypes of Web-based, patient-centred portals have been

demonstrated to support self-management of illness and enhance understanding of the complications of poorly controlled disease (Berendt et al. 2001; deClerq, Hasman, and Wolffenbuttel 2001). Patients living with chronic illness are also more likely to use health information than their healthier counterparts (Hejlesen et al. 2001), although each chronic illness has specific, recognizable challenges for affected patients in symptom comprehension, information management, task fulfillment, and social interaction (Wagner and Hibbard 2001).

The Case for Personalization in Self-Managed Care

To date, research demonstrating the benefits of patients accessing their own health record has been mixed at best (Ross and Lin 2003). First, the most appropriate group (chronic-care patients) is often not targeted. Second, letting patients have access to advanced hospital information systems does not truly measure their appetite for their own health information delivered within their own environments, in the form and manner they wish to receive it. Winkelman et al. (2005) suggest that inconsistent results related to the impact of patient-centred information tools (such as patient-centric Electronic Health Records) may be caused by a lack of clear understanding and definition of the patient viewpoint. Early-adopter patients will not only want access to their own health information, but will want to be able to understand what it is they are reading. In addition, they will want to know the information that is specific to their illness or disease, and information on treatment options and health outcomes that is most relevant to their condition. We believe that effective self-managed healthcare should involve the personalization of health information: with individually and contextually tailored information, the patient would be both better-educated about their specific condition and better able to enter into a dialogue with their physician to make informed decisions about their treatment. Personalized health information will be a key element in effective self-managed healthcare (Kreuter et al. 1999; Maibach and Parrott 1995), with great potential “to enable citizens to take more control of their well-being, by accessing personalised and qualified health information, both medical and pedagogical, and accessing appropriate medical care from their homes” (Personalisation in e-Health Workshop, User Modelling Conference, 2005).

Automated Generation of Tailored Health Educational Materials

Over the past few years, several systems have been developed to provide patients with access to parts (or all) of their EHR (Abidi, Han, and Abidi 2001; Cimino and others 2001; Ueckert and others 2003). Two significant studies have been published recently exploring patient attitudes to accessing their EHRs online (one from the National Health Service in the United Kingdom and one from the Geisinger Health System in United States) (Pyper and others 2004; Hassol and others 2004). Despite the importance of these studies, the findings raise more questions than they answer.

There are still large gaps in our understanding of why patients access their records online, what elements are important, what restrictions should exist, what types of support are required, how information and education should be provided through the record and how the impact on the patient-provider relationship should be assessed. Furthermore, there are challenging questions about how complex and technical data that could be confusing or anxiety-provoking should be presented to patients. We propose to address this latter aspect through self-managed access to individually tailored health information materials, concentrating on diagnostic reports.

The case for personalization of health information is supported by studies in health communication which have shown that health-education material can be much more effective if it is customized for the individual patient in accordance with their medical conditions, demographic variables, personality profile, or other relevant factors (Campbell et al. 1994; Skinner, Strecher, and Hospers 1994; Strecher et al. 1994; Kreuter et al. 1999). A special issue of *Patient Education and Counseling* (February 1999) reviewed key work in computer-generated tailoring of health information, including: smoking cessation (V.J. Strecher; W.F. Verlicer and J.O. Prochaska), nutrition (J. Brug et al.), and potential benefits of tailoring (D.S. Bental, A. Cawsey, and R. Jones; A. Dijkstra and H. De Vries). The emergence of “Information Therapy” is a growing phenomenon but a number of forums have presented its potential significant benefits to both patients and hospitals¹. Researchers in Natural Language Generation have begun to apply methods from Artificial Intelligence and Computational Linguistics to develop automated systems for tailoring health information to individual patients, for example: (Binsted, Cawsey, and Jones 1995; Reiter and Osman 1997; Bental, Cawsey, and Jones 1999; Reiter, Robertson, and Osman 2003; Green 2004).

Research Challenges in Providing Tailored Access to Medical Records

We are focusing on providing self-managed access to tailored diagnostic reports that will be automatically generated from the patient’s electronic health record. The reports will be delivered in at-home or other personal settings, on a variety of information devices. Automated tailoring of diagnostic reports presents a number of research challenges.

Jargon: domain specialization of language

The language of diagnostic reports is often complex ‘medicalese’ that is not readily accessible to the average layperson. We need to ‘de-mystify’ the medical language in these reports to present the content in terms the patient can understand. There has been a plain-language movement in health and wellness for over fifty years, and it has made some important progress in the way medicine is both taught and administered, but it has traditionally been concerned only with reducing jargon and syntactic complexity. While both of

¹A central clearinghouse (<http://www.informationtherapy.org>) now exists to promote this new field, and make available key resources for both researchers and the healthcare industry.

these strategies are sound, the changing demographics (situations of need) and information-delivery devices (situations of use) mean that there are increasingly more challenges to face. Even when complex information can be successfully rendered into plain, simple, clear language, we are not in a one-size-fits-all situation. Further, the overwhelming explosion of health information means that we need to explore automated methods not only of reducing linguistic complexity but of filtering and tailoring the information to specific constituencies, for specific purposes, on specific devices.

Detail: different amounts appropriate to different patients

Patients differ widely in their situations of need and general medical knowledge about their specific disease, as well as their literacy, their dialect, their cultural and cognitive dispositions. We need, for instance, to account for the situation that some patients may wish to receive a comprehensive description of their diagnostic information, possibly linking in material about their co-morbidities, while others may prefer only a summary of information most essential to their understanding of their health concerns.

Language competence: idiolects and dialects

Linguistic and multicultural issues are particularly critical. The 2001 census revealed that over five million people claim neither official language as their native tongue (Statistics Canada 2002). While non-official language information provision is a possibility in the future, the more immediate need now is for English tailored to second-language speakers, one of our long-term goals. This second-language situation exacerbates unfortunate literacy difficulties, which are especially problematic in situations of health and wellness. Many people have low literacy, so they cannot make use of health information because it is written at too high a level. Additionally, many citizens speak a variety of English that developed elsewhere (Indian English, or Jamaican English, for instance), and small differences in vocabulary can often make critical differences in understanding. A narrow strategy of reducing lexical complexity will not work if the simple term that is used is not dialectically appropriate.

The HealthDoc Approach to Generating Personalized Health Information

Our HealthDoc approach is similar to other health personalization projects in its underlying goal of providing more relevant, patient-centric health information. However, our approach aims to produce high-quality, finely tailored texts by avoiding the difficult problems inherent in generation ‘from scratch’: we rely instead on the pre-authoring of a library of reusable content variants (the “Master Document”), and a subsequent process of customization in which reader-appropriate pieces of text are selected, re-assembled, and automatically edited—‘repaired’—by computational linguistic engines.

This paradigm, ‘generation-by-selection-and-repair’ (DiMarco, Hirst, and Hovy. 1997) was implemented in a tailoring engine (DiMarco et al. 2005) and prototype text-repair

engine (based on Wanner and Hovy’s (1996) sentence-planner design). We are developing a suite of ‘repair engines’ to carry out various types of textual repair, starting with simple surface repairs and proceeding to more-complex deep-syntactic repairs. Surface repairs involve detecting faults such as excessive repetition, as in the following sentences:

- (1) *Non-insulin-dependent diabetes* is the most common type of diabetes.
- (2) *Non-insulin-dependent diabetes* usually develops in adults over age forty, especially those who are overweight.

In this case, the repetition is not syntactically incorrect, but sounds clumsy. The text would read more smoothly if the second occurrence of the repeated noun phrase were replaced by the pronoun *It*. Other forms of surface repairs can involve *lexical choice*, as in replacement of a repetitive word or phrase by a near-synonym, or *aggregation* to combine sentences to remove the redundancy.

Our current work also involves development of a Physician’s Authoring Tool to assist the writer in creating the repositories of content variants (i.e., the Master Documents) from which customized versions will be generated. We are developing an authoring environment which embodies our paradigm of generation by selection-and-reassembly, together with formal models of learning and rhetorical theory (Kelly, McDougall, and Abbott 2009) to allow domain expert (e.g., health educators) to interact directly with our tailoring system to create the Master Document repositories that can then be selected, processed, and assembled into readable, client-specific, educational material.

The HealthDoc health message tailoring software has also been adapted to provide customized sets of recipes and food-use tips about fresh vegetables to clients of charitable pantries (Evans, Clarke, and Hovy 2009). This was an effort toward primary prevention of obesity and other diet-related diseases among low-income people, millions of whom depend on free food gathered by non-profit food banks and distributed through community agencies. Evans, Clarke, and Hovy conducted a field test of their tailoring system, Quick!Help for Meals, at six pantries, across ten different occasions of food distribution per site. Tailored pantry visitors reported significantly greater use of supplementary vegetables than visitors who received a generic set of all recipes and tips that were available.

Conclusion

The healthcare system must begin to build specific programs for patients whereby they can more effectively access, and make use of, their own health information and make sound health and medical care decisions. Personalized health information delivered through self-managed access to the patient’s electronic health records will provide patients with the ability to take advantage of their own knowledge and experience, resulting in greater patient satisfaction with treatment and outcomes, a reduced need for services, and significant cost savings.

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