

Navigation in Internet-based personal healthcare records: for consumers who think

Benjamin Fry¹, Jim Warren²

¹ University of South Australia, Advanced Computing Research Centre, Adelaide SA, Australia

²The University of Auckland, Computer Science – Tamaki, New Zealand

Abstract

Internet-based personal healthcare records (PHRs) are designed to be created and maintained by individual healthcare consumers, based on their own understanding of their health conditions. Based on historical hypertext systems and working from a series of consumer use cases, we examine the options for end-user navigation in PHR systems. A prototype Internet-based system to support four paradigms of navigation – document-centred, node-centred, path-centred and graph-based – has been implemented. The system supports PHR organisation and annotation, as well as discussion of contents among stakeholders (e.g., doctor and patient). The architecture demonstrates the integration of existing packages on the client and server ends, including use of the widely-installed Adobe Acrobat. The system is intended to provide some of the appropriate tools for the up-and-coming variety of health consumer who wishes to be an active participant in their own healthcare, who wishes to understand and contemplate their health record. Both user interface and architectural design aspects are offered as concept templates for PHR system implementation.

Keywords: consumer health informatics, hypertext, patient-provider communication

1. Introduction

Internet-based personal healthcare records (PHRs) are an emerging technology which allows people to coordinate and access their lifelong health information and make appropriate parts of the record available to those who need it [1]. A key component of PHRs is the provision of an integrated view, which allows individuals and their authorised representatives to control their personal health information, supporting them in managing their health and wellbeing, and enhancing their interactions with health providers [1].

Many patients have a strong desire to access their record. In the US, 79% of patients were either “very interested” or “somewhat interested” in

reading their clinical medical record; in the UK 83% of surveyed patients endorsed patient-accessible records, with roughly half wishing to view their records using a computer [2]. Chronically ill, frequent users of health care, and people caring for elderly parents, report the highest and “most urgent” interest [1].

Patients generally believe that the ability to access their medical records will improve a number of elements in the healthcare process [1-2]: improving doctor-patient communication; increasing patient adherence to treatment; facilitating patient education; and empowering the patient. Studies that evaluate experiences of patients and physicians in clinical trials of on-line medical records [1, 3-4]

have confirmed the anticipated benefits of access. A randomised controlled trial [3] showed that patient access to their record gave benefits such as: learning more about their condition, coordinating care, learning about medical decision making, reinforcing their memory of the visit, streamlining certain processes, and confirming the accuracy of the medical record. Another benefit is that the patient gets to have a record of their health history to share with other providers [1, 4].

Focus group findings from the “Connecting for Health” initiative found that while “participants liked the idea of keeping their medical records online, they were disappointed in the functionality of the tools provided to them” [1, p. 31]. Specifically, participants criti-

cised their design and navigation, making comments such as “the tools were not user friendly,” “entering information was not easy,” and that it was too difficult to consolidate records from different providers to document their entire health care experience [1, p. 31].

Hassol et al. [5], while acknowledging that the majority of patients were satisfied with the use of their medical record, found that one third of respondents felt that the personal health information contained in their electronic health record was not complete, and approximately 25% of patients felt that their medical history was not entirely accurate. Earnest et. al. [3] identified patient preferences for some means to annotate their records in order to rectify these errors. Other identified preferences include the provision

for an edited form of the record that is easier to understand and the provision of hyperlinks to define technical terms.

Hypertext system developments over the past 20 years provide potential models to address the deficits identified in [1] and desired features as indicated in [3]. In this paper we arrive at a system design, prototype architecture and user interface through analysis of past hypertext systems and PHR system user cases. The design is oriented toward openness in communication, as well as in use/re-use of software components to achieve the appropriate user interaction. The goal is to identify how to build PHR systems that help consumers who wish to understand and contemplate their health record, integrating with an overall program of IT for consumer empowerment.

2. System Design Method

It is proposed that advanced hypertext techniques can be utilised to facilitate the individual and collaborative tasks in PHRs. The available literature and historical prototypes are in fact quite extensive. Notable historic hypertext systems include NoteCards [6], KMS [7] and gIBIS [8]; good review perspectives include [9] and [10].

We propose an extended browsing paradigm for PHRs that offers the following features of previous hypertext systems:

- an extended form of navigation supporting four browsing paradigms;
- the ability to collaboratively

Knowledge Structuring and Annotation Use Case

- 1) Patient collects an assortment of information from their health providers over their entire lifetime to place into their PHR. These documents are in the form of computer printouts and photocopies of handwritten notes.
- 2) Patient scans this information into a computer, logs in to their PHR, and uploads their information to the PHR.
 - a. In the process the patient adds further contextual information in an attempt to structure and sort the information they have. This may include temporal structuring or ontological structuring:
 - i. Temporal: e.g., “This information is about a hospital visit on the 21st June 1994 and this information is about a doctor’s visit on the 24th August 1994”.
 - ii. Ontological based on category of document: e.g., “This document is a blood-test and this document is a hospital discharge summary”.
 - iii. Ontological based on disease: e.g., “This CAT scan, discharge summary, and psychiatric notes are in relation to my major depression”
- 3) The patient, after uploading their information, looks through it and identifies further relationships between documents.
 - a. Temporal: e.g., “This pap-smear test was a result of this doctor’s appointment”, “This hospital stay on 21st June 1994 was a follow up from the stay on 1st March 1994”.
 - b. Based on a disease: e.g., “This doctor appointment resulted in a diagnosis of Attention Deficit Disorder whilst this second opinion of the same symptoms resulted in a diagnosis of Petit Mal Seizures”, “This list of medications is due to my diagnosis of Crohn’s Disease”.
- 4) The patient, after uploading their information, also identifies a number of statements in particular artefacts on which they wish to add commentary.
 - a. Clarification: e.g., “This point made is not true. I only said I hadn’t had sex in four years to get out of all the sexually transmitted infection tests that the doctor wanted me to have.”
 - b. Opinion: e.g., “I do not agree with this point the doctor has made. He says my condition has improved but I have been feeling a lot worse.”
- 5) The patient, after uploading their information, identifies a number of questions they have based on the contents of their PHR, to bring up with their GP: e.g., “This EEG says my alpha rhythms are of low voltage beta frequencies at around 15-20Hz. What does this mean? Is there anything wrong with this value?” Doctor could review these online or patient can print to take hardcopy to doctor.
- 6) As the patient continues with their life, they continually add new artefacts to their healthcare record, either by scanning the documents in or through a form of electronic transfer initiated by the healthcare provider. This includes continual repetition of steps two through five.

Figure 1: Major system use case for Internet-based PHR

annotate all aspects of the PHR; and

- the provision for external integration of the PHR with third-party applications.

We see four browsing paradigms as each applicable to the PHR:

1. *Document-centred* navigation organises nodes into a hierarchy of document types.
2. A *node-centred* view is focused on one node, as per a contemporary Web browser (although browsers are weak on the annotation possibilities of this view).
3. A *path-centred* paradigm (also known as path-building or trail-blazing) aims to connect a chain of links through an information space and provide a context for understanding this series of document nodes.
4. *Graph based* navigation or ‘spatial hypertext’ [11] emphasises the implicit relationships, emergent structures and leveraging of pattern recognition implied and enabled in the layout of a collection of nodes and arcs.

With hypertext annotation, readers are able to respond to hypertexts with commentary, make new connections and create new pathways, gather and interpret materials, and otherwise promote the accretion of both structure and content [12]. Our concept of external integration is inspired by Microcosm [13], which as a precursor to the Web aimed to allow any application to contribute to the hypertext system in the form of both content and processes. The motivation for this goal was to support and integrate with commonly used tools in the desktop environment, and hopefully bring the use of hypertext systems to the mainstream.

Use cases – i.e., behaviourally related sequences of steps (scenarios) for a task (as per [14] and [15]) – set the requirements for the PHR system employing the extended browsing paradigm. Figure 1 provides a main PHR use case around a patient structuring and annotating their data. Another major use case is for Online and Offline Communication, which can begin with a patient identifying interesting information on the Web, uploading it into the PHR and creating links and

annotations to relate the information to their medical data (e.g., to indicate interest in an alternative therapy). This use case proceeds with printing of the context for taking to a healthcare encounter, or on-line contribution to this new PHR context by a healthcare provider. A final major use case concerns Complex Navigation where a patient, patient advocate or healthcare provider traverses components of the PHR to gain insight into a patient’s illness.

3. Resulting System

The PHR system has been implemented with a classic three-tiered architecture (Figure 2). Presentation logic is written with Java Server Pages that interface with JavaBean classes. These JavaBeans provide the business logic for the system and interface with the data layer. The JavaBeans are separated into three packages: PHR.Controller offers general functions to facilitate the PHR’s processes; PHR.Object provides an object-oriented representation of the PHR data; and PHR.Data provides the functions to access the relational database layer

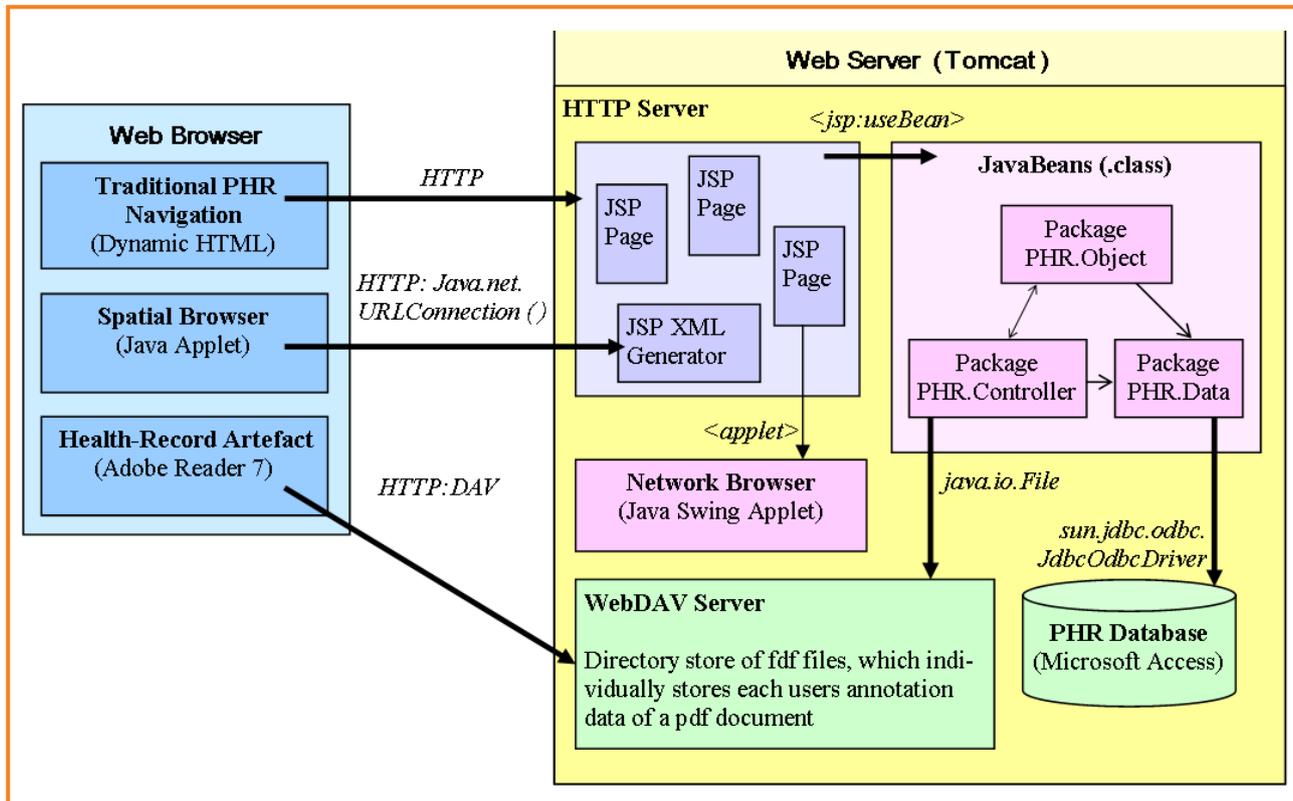


Figure 2: System architecture supporting multiple navigation

Personal Health Record for Benjamin Fry

You are currently viewing a **specific document** in your PHR. To return to your PHR click [here](#).

Biochemistry Test - 11/05/02
Artifact Summary / [Artifact Annotations](#)

Author(s): Pathology Department - Queen Elizabeth Hospital
Uploaded by: Benjamin Fry on 19/10/2005

Contextual Navigation:
This artifact belongs in the following areas:
[Diabetic Ketoacidosis](#): Previous / Next
[Hematological](#): Previous / Next
[10/05/02 Hospital Stay](#): Previous / Next
[Add another context to this document](#)

Click [here](#) to display a graphical representation of the associations to this artifact

Annotation:
This artifact has 2 annotations:
[Note: My blood sugar...](#) (author: Benjamin Fry)
[Note: This blood/gluc...](#) (author: Jim Warren)

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THE QUEEN ELIZABETH
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CRAMOND CLINIC PSYCH

Question - fryb 19/10/2005 3:09:18 PM
My blood sugar seemed to be this low throughout my whole hospital stay. Did this contribute to the Ketoacidosis?

Reply 1 - fryb 19/10/2005 3:09:20 PM
This blood/glucose level, while slightly low, is no cause for concern

Sodium	141	mmol/L			
Potassium	4.1	mmol/L			
Chloride	97	mmol/L			
Bicarb	24	mmol/L			
Anion Gap	24	mmol/L			
Glucose	3.6	mmol/L	(3.8 - 5.5)Fast		
Urea	4.6	mmol/L	(2.7 - 7.2)		
Creatinine	0.090	mmol/L	(0.050 - 0.120)		
Urate	0.33	mmol/L	(0.25 - 0.50)		
Phosphate	0.98	mmol/L	(0.80 - 1.45)		
Magnesium	0.88	mmol/L	(0.70 - 0.95)		
Protein	81	g/L	(60 - 80)		
Tot.Bili	18	umol/L	(6 - 24)		
GGT	22	U/L	(0 - 60)		
ALP	111	U/L	(30 - 110)		
ALT	22	U/L	(0 - 55)		
AST	19	U/L	(0 - 45)		
LD	131	U/L	(110 - 230)		

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BIOCHEMICAL ANALYSIS

NOTES PHONE APPT FILE
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Figure 3: Node-centred navigation: uploaded document with question-and-reply in annotation using Adobe Acrobat (confidentiality note – real pathology record supplied with permission from patient [BF] with fictionalised comments)

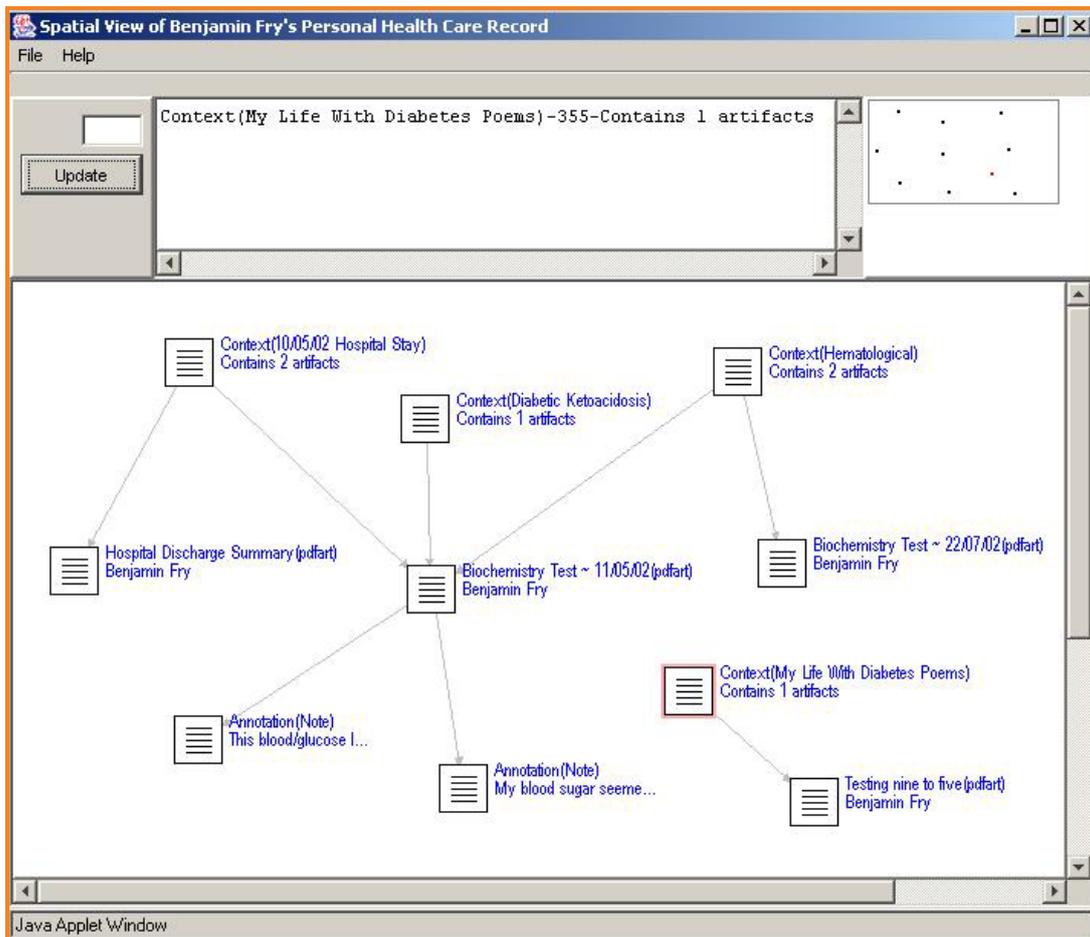


Figure 4: Graph-based navigation showing artefacts relating to a hospital stay (confidentiality note – based on, but simplified and somewhat fictionalised from, an actual hospital stay by the first author).

of the PHR.

Document-centred navigation is provided via a standard set of contexts (including ‘Health Issues’, ‘Healthcare Encounters’ and ‘Important People’) which the user can extend and add sub-contexts to. The annotation extensions available with Adobe Acrobat 7.0 are used to support the node-centred view. Comments on a PDF file are stored in a separate FDF file that is updated on the server using WebDAV (World Wide Web Distributed Authoring and Versioning). Figure 3 shows the user interface with the node-centred view; path-centred navigation (moving within and creating contexts) is supported in the right-hand panel of the screen. Figure 4 illustrates the graph based navigation user interface, which uses the Biblignost [16] tool for graphical viewing of contexts.

4. Discussion

From its origins with Vannevar Bush’s ‘memex’ [17], hypertext has been intended as a technology to support individual thought. We have illustrated a PHR system design oriented toward supporting a health consumer in thinking about their PHR. The four distinct navigation paradigms each have potential to encourage a distinct way of seeing and thinking about the health record data. Different paradigms will favour different learning styles, personalities and functions. For example, one can imagine a health consumer predisposed (or forced by the sheer complexity of their record) to wish to organise their data with the hierarchical document-centred view. Alternatively, the free-form layout of the graph-based navigation view may be most helpful for a consumer who wishes to engage in deep contemplation of a series of healthcare events, and who perhaps is attempting to apply their innate creativity to ‘sense making’ about the illness of themselves or a loved one. In so doing they may arrange and link various events in their record, as well as including links to external materials.

Equally as important as the specific paradigms and the ways we have ren-

dered them in the prototype is simply for designers to remain mindful that a wide range of options are available, and to avoid falling into the trap of designing purely on the basis of what is most expected or readily supported by current tools. The (legitimate) heuristic of providing users with a familiar experience should not overwhelm other design considerations. That is to say that designs based on previously successful Websites may fail to deliver a full range of functionality to support a thoughtful health consumer in working with their PHR.

One area where we should not be lulled by the design conventions of recent years is in the end-user authoring and collaborative authoring possibilities of hypertext. The architecture of the Web Browser and Web Server creates a distinction between the content viewing user (who has a browser) and the content creator (someone with access rights on a server). One can think of the ability to ‘publish’ on the Web as providing a metaphorical printing press - publishing capability alone, however, leaves the readership in ‘read only’ mode, and is antithetic to the original nature of hypertext. The past few years have seen collaborative hypertext become more common on the Internet, notably in the form of wikis (esp. the Wikipedia, but also local purpose-specific wikis, such as wikiCancer [18]) and web logs (‘blogs’). With conventional wiki technology the degree of expression in terms of typography and layout is still limited [19]. The concept of collaborative postings that include video, as illustrated by YouTube [20], is making the notion of dynamic and collaborative hypertext on the Internet more colourful and well-known, if not semantically richer. We must continue to challenge the prevailing paradigms for user interfaces to Internet-based content to open up options for the PHR and Internet-based support of health consumers in general.

One can identify at least five distinct technologies to enhance a health consumer’s ability to engage cognitively in their own health care [21]:

- Internet Search Support – tools to help consumers find the right gen-

eral health information for their needs;

- Agenda Support – tools to help consumers identify their needs and questions (such capability is illustrated in [22]);
- Lifestyle Support – tools that help consumers to make and stick to relevant health-enhancing decisions, such as trying to quit smoking (e.g., [23]);
- Online Communities – where consumers share knowledge and experience, and provide mutual affirmation; and
- Consumer Participation in the Electronic Health Record (EHR) – tools that help the user to view and contribute to the records kept by the healthcare system.

The prototype described in this paper suggests design elements that cross all of the five consumer support technology areas listed above. Annotation of the PHR can help a consumer to record and position the results of Internet searches; formulate agendas; record and track progress on healthcare plans; create interpretations and queries to offer for feedback from others (healthcare providers or a lay community); and, if linked to mainstream healthcare systems, can provide an avenue for consumer participation in the EHR. Our approach to re-use of components in the system architecture is amenable to ongoing experimentation and exploration of the available modes of consumer interaction with the PHR.

Tang et al [4] find that the consensus in the literature is that most of the benefits of PHRs are maximised where there is an explicit integration of the EHR of the ‘mainstream’ health care system to the PHR. Relying on the consumer to always remember to get EHR extracts to add to their PHR is likely to be suboptimal. Moreover, smooth integration of the PHR and the General Practitioner’s patient management systems holds particular promise for promoting doctor-patient partnerships that engender consumer adherence to a negotiated care plan. Gaining healthcare provider participation in correspondence initiated from

the PHR will be an emerging issue, perhaps not unlike the initial reactions of physicians to consumers bringing printouts off the Web into their consultations.

5. Conclusion

There is a great interest in Internet-based Personal Healthcare Records (PHRs), and some evidence of their great potential, as well. The maximum benefit will be realized from these technologies when they support a full range of navigation and annotation features. We have provided an example architecture and user interface for an Internet-based PHR with extended browsing features. Much is to be learnt from end-user experiences; hence a field trial is the most obvious outstanding area for future research. The system in its current form is best tailored to a particular class of user (patient or patient advocate): one that is highly motivated to compile and organise PHR data (perhaps due to anxiety over the mounting complexity of their record or frustration with the process of care); and also a user who is fairly computer-savvy (e.g., able to use a scanner and work through Acrobat). One size will *not* fit all in the PHR world. Aspects of the design and implementation illustrated here may be informative to PHR implementers working to any of a broad range of user profiles and use cases.

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Correspondence

Prof Jim Warren
Computer Science - Tamaki
The University of Auckland
Private Bag 92019, Auckland
New Zealand

Phone: +64 (0)9 373 7599
Fax: +64 (0)9 373 7503
<http://www.cs.auckland.ac.nz/~jim/>

jim@cs.auckland.ac.nz