Towards an Accessible Personal Health Record

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Abstract. Patient empowerment frameworks and personal health records (PHRs), engage technology empowered citizens in self-managing their healthcare. Increases in the frequency of chronic diseases, the population of elderly and disabled people, and cross-border patient mobility, can render such systems lifesaving, cost effective and time saving. Several online applications are promoted as being functional, user-friendly and detailed enough to provide a complete and accurate summary of an individual's medical history. However, most of these services do not fully adhere to accessibility standards, thus turning them away from people with disability and the elderly, who prove to need them most. Support for mobile devices introduces additional obstacles to users with disability when trying to operate such services. This paper presents fundamental guidelines for the successful implementation of accessible ePHR services that can be operated by any patient, including people with disabilities, and through any device used..

Keywords: E-Accessibility, WCAG, Disabled people, Personal health record (PHR), Accessible electronic PHR (ePHR).

1 Introduction

Personal health record (PHR) systems are widely used to maintain a dynamic and up-to-date health profile, including a variety of different data that are not necessarily limited to medical family history, medications, laboratory tests, diagnostic studies and vaccination, but may also contain lifestyle information, medication compliance data, emotions, physical activity, etc. These records are intended to provide a complete and accurate summary of an individual's medical history in order to be useful, as well as (re)usable for clinicians and healthcare professionals to correctly evaluate the condition of a patient, without the need for time consuming and costly examinations. Thus, there exists significant value in making this information accessible online for all citizens, while complying with patient data privacy and security ethics.

In western countries, e-accessibility of public information and e-services, including ePHR, provided by governmental agencies (e.g., health insurance organizations, hospitals, etc.), is mandatory by law. For instance, in the U.S.A., "The Americans with Disabilities Act of 1990" [1], applies to all goods and services provided by the government and requires that all public facilities, not just those receiving federal funding, be accessible to the disabled population. More specifically, websites and e-services are required to comply with the technical provisions of the U.S. Rehabilitation Act of 1973 (Sections 504 and 508 – a subset of WCAG 1.0 with a few additions) [21], [22]. In the European Union, besides on-going legislation in some Member States, latest policy developments include the eHealth action plan to facilitate a more harmonious and complementary European approach to eHealth, with specific references promoting the accessibility of eHealth services, particularly for elderly or disabled persons [8]. With regards to technical specifications, the W3C's Web Content Accessibility Guidelines (WCAG) 2.0 has been adopted as the de facto accessibility standard (adopted also in Australia, Canada, France, Germany, Greece, Hong-Kong, Ireland, Italy, New Zealand, UK and elsewhere [10]). Besides those specific policy cases and technical specifications, it is also worth mentioning Article 25 of the UN Convention on the Rights of Persons with Disabilities, which states that "States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation" [20]. However, despite the worldwide recognized importance of e-accessibility, several studies indicate that many available e-services, based on visual concepts, are largely inaccessible to the elderly and to people with disability [5], [6]. More specifically, concerns indicate poor or no integration of specific technical accessibility requirements, while usability barriers are recorded on PHRs usage by elderly, disabled, and immigrant patients [7], [12], [13], [19], [29]. Therefore the need for indentifying Universal Access design challenges is more prominent than ever. Thus, appropriate design processes and methods must be applied to existing or to the newborn eHealth care platforms with smart surroundings.

According to the HIMSS (Healthcare Information and Management Systems Society) an ePHR is supposed to be "*a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools*". It should therefore be operated by the patient himself, aiming at the provision of access to such services for anyone, anywhere and at anytime, through any kind of devices. Such an approach implies an explicit design focus to address diversity, as opposed to reactive or ad hoc approaches, and additional consideration towards redefining the concept of *Design for All* in the context of Human Computer Interaction [15]. In that context, as an ePHR is a health record that is handled by an individual user himself, it is necessary to make this information accessible online to anyone who has the necessary electronic credentials to view the information.

In addition to functional limitations, someone has to also take into account that users increasingly demand more freedom to choose their preferred hardware-software combination (i.e., iphone or android mobile devices) for accessing all kinds of e-services through the browser of their choice. Following this trend, new and existing e-services are being (re-)designed in order to be accessed through mobile devices, as well as traditional PCs. However, as recent studies indicate, e-services which are designed basically for visual interaction are largely inaccessible to people with disability, raising as a consequence barriers to mobile device users as well [23].

As with a typical e-service, the development of a fully accessible and interoperable ePHR introduces new challenges to the accessibility provisions that have to be adopted from the early design stages [2], otherwise development costs rises [3]. Due to the importance of the ePHR in comparison to other e-services, the design process is even more demanding compared to a typical interoperable e-service [4], [9], as the considerations mentioned previously have to be carefully addressed.

This paper evaluates some of the most widely used ePHRs (section 2) and presents specific design characteristics addressing accessibility and usability considerations that should be taken into account aiming to the development of a fully accessible ePHR, available through mobile devices as well as traditional desktop PCs equipped with assistive technology. We argue that an electronically accessible PHR web based service (ePHR) must be offered directly to individuals, so that information can be inserted, at a later (or earlier) stage during a medical/clinical act, accurately, via online web based forms or other kind of online software tools linked directly with their personal record. Our contribution, in this paper, is to identify the main challenges and propose specific (experience - based) design guidelines that web developers must follow in order to comply with WCAG 2.0 [24], as well as with the *Mobile Web Best Practices* version 1.0 [25].

2 E-Accessibility Support for ePHRs

Recent advances of the Web 2.0 and wireless network communication have altered the traditional way people, including those with disability and the elderly, use computers and e-services. Now people engage in social networks, perform various everyday activities and are willing, to a certain extent, to share personal health data. Microsoft HealthVault (http://www.microsoft.com/en-us/healthvault), Google Health (http://www.google.com/intl/en-US/health/about), Patientslikeme (http://www.patientslikeme.com), PatientSite (https://www.patientsite.org), WebMD Health Record (http://www.webmd.com/phr), MyPHR (http://www.myphr.com/), My Revolution of RevolutionHealth (http://www.revolutionhealth.com/my-revolution/promo) and NoMoreClipboard.com (http://www.nomoreclipboard.com) are only some of the well-known available Web-based ePHRs, mainly based in U.S.A., that enable the patient to manage health data such as medical family history, medications, laboratory tests, diagnostic studies, surgeries, vaccination, and allergies. In addition to this basic functionality, some PHRs provide extra services such as drug interaction checking or messaging between patients and medical providers. One question that arises is whether disabled or elderly people could utilise this functionality, or if these services can be operated effectively with the use of assistive technology solutions.

In order to determine the e-accessibility level of these representative ePHRs, they were evaluated against WCAG 2.0 conformance level AA. The evaluation was carried out during the period October 2010 to June 2011 and the test sample included at least 5 different web interface screens from each ePHR (e.g., submission forms and view pages). The tools used for the evaluation were the TAW [16] and Total Validator [18], supported by manual testing provided by experts to ensure the accuracy of the automated assessment (in cases of manual checks). The manual testing included rendering without style sheets, scripting on–off, alternatives to JavaScript, use of placeholder images without alternative text, accuracy of alternative text description of content images, markup validity pseudo errors, presence of frames, disturbing animation, image-maps, pop-ups, utilization of keyboard, deprecated techniques for text alignment, etc. The results of the automatic testing conducted across this sample, supported by manual testing by experts to ensure the accuracy of the results of the automated assessment, found poor e-accessibility conformance results. As Table 1 indicates, none of the aforementioned ePHRs achieved Level AA conformance of WCAG 2.0 that ensures good accessibility level for several categories of disabled and elderly individuals.

Table 1. E-accessibility evaluation of eight selected ePHRs mainly against WCAG 2.0.

Service Name	WCAG 2.0 level AA Conformance	Markup Validity	Mobile version (MWBP 1.0)
Microsoft HealthVault	Fail	Fail	N/A
Google Health (discontinued)	Fail	Fail	Iphone App N/A
Patientslikeme	Fail	Fail	As Desktop – N/A
PatientSite	Fail	Fail	As Desktop – N/A
WebMD Health Record	Fail	Fail	As Desktop – N/A
MyPHR	Fail	Fail	As Desktop – N/A
My Revolution	Fail	Fail	As Desktop – N/A
NoMoreClipboard.com	Fail	Fail	As Desktop – N/A

Such trend is not surprising. Similar findings related to inadequate e-accessibility levels have been also reported diachronically for e-services in general [5], [6], [14]. Up to early 2000, Web (mainly static) content was comprised mostly of text with images and interactive Web forms. These types of components could easily be identified by assistive technologies (e.g., Braille display, screen reader, enhanced keyboards, switches, etc.). However, the newly introduced Web technologies utilize new features that can cause problems to disabled Web users, especially those using screen readers. Such problems include:

- inaccessibility of built-in refreshable scripting technologies that triggers the browsers XMLHttpRequest object and cannot be handled by current versions of screen readers (although WAI-ARIA [26] is making progress in this specific area)
- lack of non-scripting alternatives or media without captioning
- in general the use of authoring practices based on a WYSIWYG metaphor
- dynamic behavior in selection of segments of content, that utilises the drag and drop interaction metaphor with a pointing device (without providing keyboard equivalent behavior)
- lack of liquid designs (for text only enlargement)
- lack of semantics in the content that provide non visual cues of information structure,
- use of embedded applications which do not provide accessibility features (e.g., Flash objects, Active-X controls, embedded video players).

Therefore, with all these technology advancements, the question arises as to whether it is possible for disabled and elderly patients to become end-users of ePHRs, since they present not only accessibility but readability [17] problems as well. Currently, the role of the disadvantaged or excluded groups, including the unskilled, the disabled and the elderly, is limited, since traditionally the delivery of these e-services has been biased towards: a) the "typical" or "average" able-bodied user, familiar with the notion of the "desktop" and the typical input and output peripherals and b) WYSIWYG notions supported by authoring tools or more sophisticated platforms and eServices, which generate final code without considering accessibility issues or the inability to use a pointing device.

It is argued that e-accessibility and device independence can be achieved only if design standards are applied from day one of the design process. In the case of an interoperable and accessible ePHR, the designer should comply with even more strict constraints than those targeted only to desktop solutions, since the screen size of the mobile device or the interaction style may be totally different compared to the desktop environment. To this end, design and usability guidelines for mobile design can contribute significantly towards ensuring that the final outcome addresses functional limitations such as visual disabilities, hearing impairments, motor disabilities, speech disabilities and some types of cognitive disabilities. From a usability point of view, applicable principles can be derived from guidelines improving mobile web usability [9]. For example, excellent usability experiments demonstrate that the most effective navigation hierarchy for use with mobile devices is one with only four to eight items on each level [2].

In order to develop multiplatform and fully accessible ePHRs, specific technical guidelines can be derived from similar e-services. The proposed design approach is built upon the flexible authoring methodology [4], [11], which has been successfully used in the implementation of the following e-services: a) the interoperable accessible portal of the Hellenic General Secretariat for Research and Technology [27] and b) the www.Ameanet.gr portal, developed in the context of the National funded project "Universally Accessible eServices for Disabled People" [28]. These guidelines imply designing according to this larger set of rules, performing tests and at the end re-evaluate and re-visit the designs, prior to any implementation. Once the design space has been documented, the resulting designs need to be encapsulated into reusable and extensible design components.

3 Proposed Guidelines

Commonly in clinical practice, taking history data by a clinician is not an easy task mostly due to time restrictions or missing/ lost information available only in paper. Medical personnel must interview the patient, prior to any medical action invoked, and complete such records as accurately as possible. In order to be able to provide such a system, for all possible actuators (i.e. patients, clinicians, etc.) and all possible access devices the necessary design guidelines that will enable the interaction of end-users with an ePHR system must be defined, allowing them to be able to share their personal health data (independently of storage restrictions, utilizing experience, environment of use, time limitations and information requested). The aim is to enable disabled, elderly, low vision and blind, keyboard / ear or other groups of users via assistive technology solutions to use these ePHR services which are currently designed only for optimal visual presentation by "able-bodied" individuals. The practical experience acquired during the design process for a number of accessible and interoperable e-services such as the ones mentioned above, resulted in the consolidation of the following fundamental steps:

1. *Identify device-specific constraints or capabilities*. In this phase the different limitations or features of the computing devices should be identified. The identified characteristics can be organized according to their type. Thus, a typical classification should contain: a) Output interaction capabilities (such as the screen size of the device, screen resolution, number of colors, speech synthesizer, etc.), and b) supported input interaction modes, such as physical or virtual keyboard, size of keys, touch screen, stylus, speech recognition, etc.). As a result, different presentation elements (implemented with the use of CSS versions) and adaptation logic (e.g., forms with more than 5 elements can be divided in more than one steps) should be used.
2. *Identify the context of use for each device and provide meaningful (sub-) sets of functionalities.* This phase comprises the analysis of the contexts of use for each device. In most cases, the devices are neither used in the same context nor interchangeably.
3. *Select the 'worst case' device for each function.* The computing device that appears to have the highest number of important limitations against all the diverse contexts of use should be selected in this phase. In most cases a mobile device is the most suitable candidate.
4. *Design the first user interface prototype according to the device-specific limitations.* Using well-established prototyping techniques, such as paper and pencil, mock ups, etc., proceed with the development of the first prototype for the selected device.
5. *Infer a generic set of requirements based on the first UI design.* Specific design requirements can emerge from the first prototype regarding, e.g., navigation, content structure, presentation, accessibility, etc.
6. *Design the user interface prototypes for the other devices applying the set of generic requirements.* Proceed with the user interface prototype development for the remaining devices taking into consideration the design requirements elaborated in the previous step. Additional design specific requirements may emerge for the alternative devices. These design artifacts can be incorporated and extend the set of the generic requirements.
7. *Decide which user interface components can be automatically transformed between the diverse computing devices.*
8. *Utilize e-accessibility standards for each interface component:* for desktop only functionality adhere with WCAG 2.0 level AA (including subjective 14.1 whenever possible), with the use of valid XHTML, while in case of mobile make use of most of MWBP 1.0 possible, and make use of valid XHTML Basic 1.1. For all those templates test against web accessibility with evaluation tools (e.g., TAW, Firefox Web development toolbar, W3C's mobileOK Checker, TAW mobileOK Basic Checker, etc.). In addition perform manual checks (e.g., rendering without style sheets, test the accuracy of alternative text descriptions, etc).

9. *Evaluate the user interface prototypes for all the different devices.* An appropriate usability evaluation methodology should be selected to identify potential usability problems in the user interface prototypes. The selection of the evaluation method depends upon several factors such as available resources, evaluators with expertise, time to complete the project, etc.
10. *Revisit the set of requirements and the prototypes according to the findings.* This stage requires an analytical review of the design requirements based on the evaluation findings, as well as a review of the user interface prototypes in order to amend potential usability problem or inconsistencies between the diverse computing devices.

4 Conclusion

This paper proposes the adoption of specific guidelines in the context of delivering accessible and interoperable ePHRs, to be used by disabled and elderly people with the same success rate as with the "able-bodied" end-users. From the results of the accessibility evaluation presented, it can be derived that well known ePHRs do not consider accessibility standards, thus present barriers to those mostly In need of this kind of services. By following a strict procedure from the beginning of the design process, it is possible to deliver fully accessible and usable e-services that can be utilized by assistive technology solutions, altering the present status quo of well known ePHRs and largely improving worldwide acceptability of such a service. This is the reason that this set of guidelines is applicable not only to a general purpose web-based application but also to any modern ePHR systems that can use this design framework in their early design stages.

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