A model for an inclusive healthcare information system

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A model for an inclusive healthcare information system

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Abstract

Healthcare organisations such as hospitals communicate both public and personal information to citizens. Accessible websites are suited for public information, but personal information (e.g. medical appointment notices) is still sent out by ordinary post in the form of text on a paper. Sometimes a person has to ask repeatedly for accessible information and is forced to adapt to the information system, rather than the other way around.

This paper presents a model for adapting information automatically to each individual's preferences and a list of such preferences resulting from interviews with persons with disabilities. The model facilitates an innovative process where a healthcare organisation and citizens work together in four steps: 1) A person's information preferences are stored in a database in the hospital's improved information system and can be updated at any time. 2) When the caregiver sends out information, a notification module retrieves the personal preferences from the database and adapts the information. 3) The person receives individualised information. 4) Preferences stored by citizens, but not yet implemented, can be used for further development of the inclusive information system. A prototype web form was then developed and evaluated by people from disability and elderly organisations.

Introduction

Healthcare organisations such as hospitals communicate both public and personal information to citizens. In recent years, there has been a focus on making public information on websites accessible and conformant to the *Web Content Accessibility Guidelines*, currently in version WCAG 2.0 [1]. Such public information includes general medical information about diseases, symptoms, treatments as well as regional and local information about how the healthcare is organised and contact details.

However, there is still no standard model for making personal information, such as medical appointment notices, accessible to individual citizens with dynamic and diverse requirements. Medical appointment notices from Region Skåne, the southernmost region in Sweden, are still sent out by ordinary post in the form of text on a paper, see Figure 1.
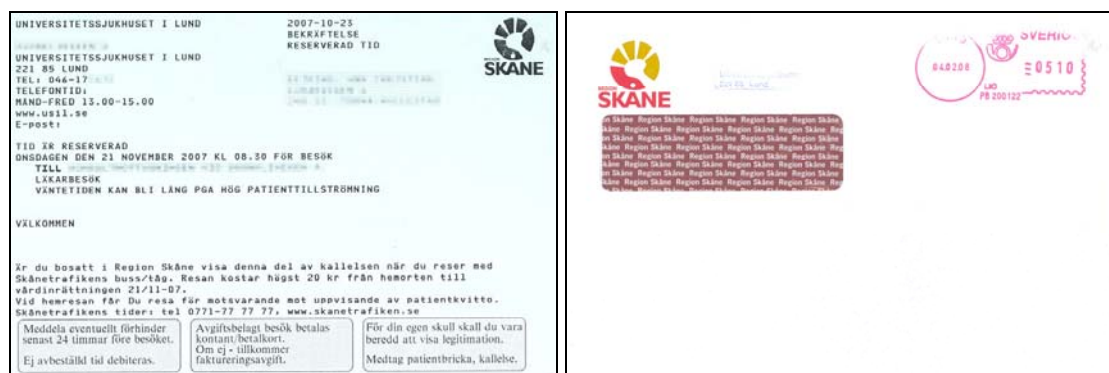
Figure 1: Currently, personal information such as a medical appointment notice is sent out by ordinary post in the form of text on a paper. There is a need for an inclusive information system.

A person has to ask specifically for accessible information every time he or she receives information in an inappropriate format. These individual requirements are not stored, so it is up to the healthcare personnel to remember them until the next time information is sent out. This is not a robust solution due to the large number of people involved. Sometimes a person has to ask repeatedly for accessible information and is forced to adapt to the information system, rather than the other way around.

Moreover, since the individual requirements are not stored, the healthcare organisation is unable to use them in an innovative process to improve their information system and make it even more inclusive.

In the current situation there is a clear need for an approach based on the concept 'design for dynamic diversity' [2] and to take 'design for all' a step further to 'design for one' [3] or 'design for me' [4]. In [4], Anderberg explains:

> '*Design for Me* consequently implies, but is not a synonym to, a high degree of adaptation with the individual. [...] *Design for Me* also implies a high level of participatory design efforts with a high degree of user involvement in the shaping of the whole support system of technological and personal assistance.'

Medical appointment notices

Region Skåne has multiple computerised information systems that process and send out medical appointment notices for different parts of the healthcare organisation. Region Skåne is planning to replace and integrate old systems with new ones when it is economically feasible to do so. In future procurement processes, there will be opportunities to also include user requirements for a more inclusive information system. Until then, medical appointment notices are sent out as variations of standard formats, depending on which part of the healthcare organisation is sending the notice.

Medical appointment notices do not only include the date, time and place for a visit to a healthcare professional or for a planned treatment. They also tell how to get to the hospital, rules for reimbursement of travel costs and how to cancel, as well as information about preparations the individual needs to make, information about the appointment or treatment itself and about what to do at home after the treatment.

According to [5], Swedish 'hospitals lose hundreds of thousands of Euros per year in patients who do not show up' for their planned visits or treatments. The reasons for these no-shows were not investigated, but appointment notices adapted to individual preferences could be one way of improving the figures. Healthcare organisations are working hard to make their services more efficient and reduce the time patients are at the hospital. Consequently, more preparation work is transferred to the patients and instructions for these preparations are attached to the appointment notices. If this information is not accessible to the patients, they may not carry out the preparations and expensive treatments may have to be cancelled when they show up.

Prerequisites for a good appointment or treatment

Appointment notices with accessible information for citizens and subsequent preparations by them are not sufficient to ensure an accessible and efficient encounter between a citizen and a medical professional. There is also information that the professionals need to know to prepare for an accessible visit or treatment. Citizens should be able to store this kind of information too, so they do not have to repeat it before every appointment.

The lack of accessibility preparations by healthcare professionals can also delay the start of the appointment or treatment and make it less efficient, causing increased cost for the healthcare organisation.

Methods

A model for an inclusive healthcare information system was developed and evaluated using an iterative development process.

First, a model that would cater to the dynamic diversity of citizens' individual preferences and support social innovation was developed. Initial interviews about this model and the diversity of preferences were carried out with representatives from disability and elderly organisations. The technical possibilities for implementing this model were discussed with a person responsible for the Region Skåne information systems. Using the results of these interviews, a prototype web form for entering individual preferences was developed. The web form was then evaluated by other representatives from disability and elderly organisations.

The model

The model in Figure 2 was developed to:
- make medical appointment notices accessible to individual citizens with dynamic and diverse requirements,
- facilitate an innovative process where a healthcare organisation and citizens work together to develop a more inclusive information system and,
- make it possible for the citizens as well as the medical professionals to prepare for accessible, and therefore more efficient, appointments or treatments.
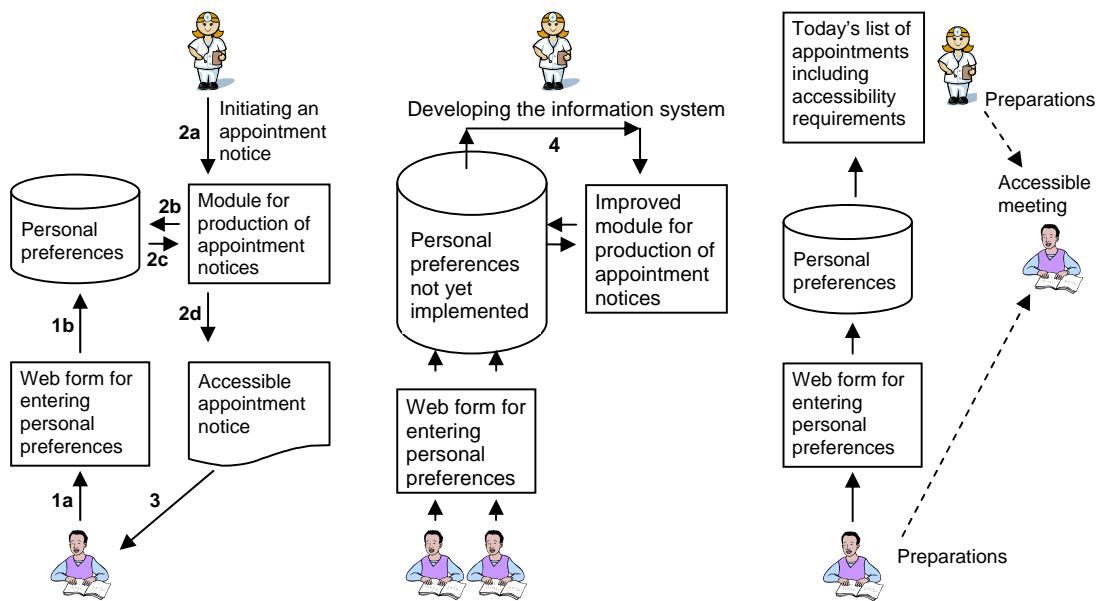
Figure 2: The model facilitates an innovative process where a healthcare organisation and citizens work together in four steps: 1a-1b) A person's information preferences are stored in a database in the hospital's improved information system and can be updated at any time. The person can also store information to facilitate professionals' preparations for an accessible and thus more efficient visit or treatment. 2a-2d) When the caregiver initiates an appointment notice, a production module retrieves the personal preferences from the database and adapts the information accordingly. 3) The person receives individualised information. 4) Preferences stored by citizens, but not yet implemented, can be used for further improvements of the inclusive information system. The model also makes it possible for a medical professional to prepare for an accessible appointment. The citizen uses the web form to store information about personal requirements for an accessible appointment. This information is retrieved from the database and included in today's list of appointments presented to the medical professional.

Preparations by both persons are needed to make an appointment accessible. The accessible appointment notice enables the citizen to be well prepared and the stored information from the citizen about personal preferences for an accessible appointment enables the medical professional to be well prepared.

Initial interviews

Interviews with the healthcare organisation

An initial two hour meeting was held with a regional expert on the large national project 'Vården på webben' (Healthcare on the Web) in order to be informed about development plans that could influence the implementation of the proposed model for an inclusive healthcare information system. The 'Healthcare on the Web' project includes the personal web service 'Mina vårdkontakter' (My Healthcare Contacts) [6], which lets citizens set up user accounts, log in and contact their local medical centres and 'request, cancel, or reschedule appointments, refill prescriptions, or ask your medical centre to contact you', see Figure 3. One can also manually 'enter notes in a calendar about

scheduled doctor's appointments'. The information transfer is encrypted and safe. An increasing number of healthcare organisations in most regional counties have recently joined this web service. It includes an embryo of the functionality for entering personal accessibility preferences, although now it is only possible to select whether the password for the user account should be sent in text or Braille.
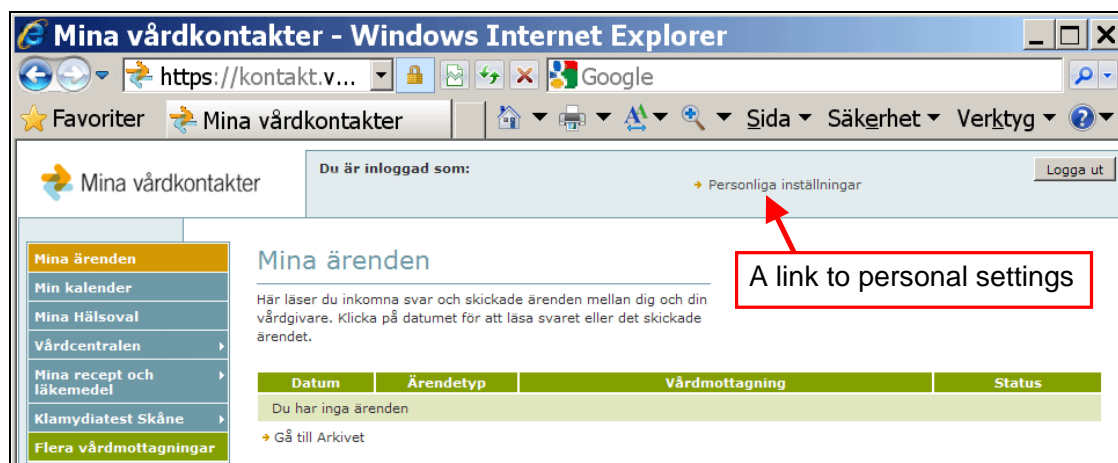

Figure 3: The personal web service 'Mina vårdkontakter' (My Healthcare Contacts) has recently been launched in most regional counties in Sweden. It includes a link to personal settings for contact details. The settings may be expanded to include the proposed personal preferences for accessible information.

The technical possibilities for implementing the proposed model were discussed with a person responsible for the information systems at Region Skåne. Before the meeting, he was sent a list of questions which he forwarded to experts of the different information systems. When he had received the answers, we had a two hour meeting to discuss the answers and possibilities.

Interviews with representatives of disability and elderly organisations

In order to get initial feedback on the need for the proposed model and to receive input for the development of the prototype web form for entering individual preferences, informal interviews were carried out with representatives of disability and elderly organisations.

The interviews were carried out at a national conference exhibition. Approximately one half hour was spent with each of the following: Pensioners' Org. in Helsingborg, Dyslexia Assoc. in Helsingborg-Höganäs, Assoc. of Hard of Hearing People in Helsingborg, Aphasia Assoc. in Helsingborg, Stroke Assoc. Öresund and Visually Impaired Assoc. in Helsingborg-Höganäs.

The model was explained to representatives of these organisations and they were asked their opinions. They were also asked to give examples of the diversity of individual needs of their members and not just their official recommendations based on a compromise among their members.

Results from the initial interviews

According to the technical experts there are many possibilities for both the web form and the database to be incorporated into existing healthcare information systems. They could either be included in the web service 'My Healthcare Contacts' or added as external modules without any connection to it.

The representatives of disability and elderly organisations were all very positive to the model for individualised information and its ability to cater to diversity. For example, the National Assoc. for Visually Impaired has a national requirement on text size of 16 points, but at their own regional meetings they use 24 points as a standard for print-outs and some individuals prefer 28 points. The Arial text font and bold style were desirable as well as other formats like Braille, DAISY and e-mail with a Word document attachment.

The Dyslexia Assoc. in Helsingborg-Höganäs wanted to be able to choose text on paper in combination with an e-mail with a sound file attachment. The text should be easy to read and understand. One individual mentioned a text size of 16 points and fonts with serifs.

The Pensioners' Org. in Helsingborg, Aphasia and Stroke Assocs. all wanted to be able to have a copy of the appointment notice sent to a relative or another person they trusted; they also wanted to be reminded the day before the appointment, for example, by a text message to their mobile phones. They preferred to have the appointment notice sent by ordinary post. The Pensioners' Org. wished for more easily opened envelopes and suggested that postcards would be quite acceptable for appointments concerning non-confidential issues. Concerning the text size, the Pensioners' Org. suggested 14-16 points and perhaps bold style, while the Aphasia Assoc. preferred 18-28 points. The Stroke Assoc. would really like to have images in the appointment notices.

There was also a need for storing personal requirements for an accessible appointment (i.e. information sent to the healthcare professionals in advance). The Dyslexia Assoc. would appreciate being able to store needs for assistance in taking notes and recording the conversation on an mp3 sound file. The Assoc. of Hard of Hearing People also wanted assistance in taking notes and to be able to inform the healthcare organisation about the need for a hearing loop or a sign language interpreter. The Stroke Assoc. wanted to inform the healthcare personnel that another person would be along so it would not come as a surprise. Receiving documentation of the discussion was also a desire they had.

On a more general level, they all liked the fact that it is individual preferences, and not impairments, that are stored in the database. People without computer experience would like it to be possible for the healthcare personnel to enter their preferences.

Development of a prototype web form

Using the results of these interviews, a standalone prototype web form for entering individual preferences was developed, see Figure 4. The web application JotForm [7] was used for the development. Some alternatives were hidden until certain check boxes or radio buttons were selected to keep the form as simple as possible.

Figure 4: Screen dumps of the prototype web form for entering individual preferences on accessible information and requirements for accessible appointments. The form can be viewed at www.jotform.com/form/2984605144.

The user can choose to have the information sent by ordinary post, e-mail, SMS and/or a message to the web service 'My Healthcare Contacts'. There are also possibilities to choose the language, to send a copy to another person and to receive a reminder by SMS or e-mail. Finally, there are two text boxes for entering information for the healthcare organisation. In the first there is a sample text saying: 'Here you can enter your need for an interpreter, assistance with taking notes, a room with a hearing loop, extra space or extra time, if a person comes along, etc...' In the second text box, one can enter additional preferences.

    If the user checks 'ordinary post' more alternatives about which physical format the user prefers are shown, see Figure 5.

Figure 5: A user who checks 'ordinary post' (left) can choose one of the following alternatives: 'Text', 'Text and images', 'Braille', 'Blissymbols', 'Spoken information on a CD (DAISY format)' or

'Sign language on a CD'. A user can choose whether the information should be sent in a sealed or open envelope or on a postcard. If 'Text' or 'Text and images' (right) is selected, a number of alternatives for text size (12, 14, 16, 18, 24, 28 points), text font (Arial, Times New Roman), text style (Normal or Bold), paper colour (White or Yellow) and UPPER/lower case letters are shown.

On the other hand, if 'e-mail' is checked, the following attachment alternatives are presented: 'Text in a Word document (.doc)', 'Text and images in a Word document (.doc)', 'Blissymbols in a Word document (.doc)', 'Spoken information in a sound file (.mp3)' and 'Sign language in a video file (.wmv)'.

Evaluation of the prototype web form

The web form was evaluated by representatives of regional disability organisations and members of a senior interest group. Three semi-structured interviews, each 1.5 hours long and based on a questionnaire with 27 questions, were carried out with people from the Visually Impaired Assoc. in Skåne, Persons with Intellectual Disability Assoc. in Skåne and the Dyslexia Assoc. in Malmö at their regional offices. Printed versions of the web form were presented to them and discussed in detail (the Visually Impaired Assoc. in Skåne was sent an e-mail version before the meeting, printed in Braille). Furthermore, shorter interviews (approx. 20 min. long) were carried out with the Aphasia Assoc. in Skåne, Persons with Neurological Disabilities Assoc. in Skåne, Survivors of Accident and Injury Assoc. in Skåne and the Rheumatism Assoc. in Skåne at an exhibition fair.

Results and discussion

Again, everyone was very positive to the proposed model for individualised information and stressed the importance of improved perceptibility and understandability of appointment notices – and they wanted it to be implemented as quickly as possible.

For the Visually Impaired Assoc. in Skåne, e-mail was the number one alternative, although it is not considered to be secure by the healthcare organisation. The web service 'My Healthcare Contacts' is secure, but the Visually Impaired Assoc. said they would need a lot of help and training to be able to log in and find messages there. On the other hand, the Persons with Intellectual Disability Assoc. really preferred the 'ordinary post' alternative, because it is physically obvious and can not be missed. They and the Dyslexia Assocs. wanted to be able to receive information in multiple formats simultaneously (e.g. ordinary post and e-mail), so using check boxes instead of radio buttons in the web form was an appreciated solution.

The Visually Impaired and the Dyslexia Assocs. wanted to add the alternative 'Telephone'. When 'ordinary post' was selected, they wanted two separate alternatives for 'Spoken information on a CD' – one with DAISY format and one with Audio CD format, because some CD players could only play audio CDs. The Persons with Intellectual Disability Assoc. wanted to add an alternative to receive a DVD with a video clip of the medical examination; they felt the Blissymbols alternative could be removed.

The Visually Impaired Assoc. did not see a need for very large font sizes (like 24 or 28 points), because appointment notices are not the type of information you need to print

out and bring to places where you do not have access to a computer. It is not like meeting agendas which you often do need in large print. Both the Persons with Neurological Disabilities Assoc. and the senior interest group had preferences for text sizes of 12, 14, 16 and 18 points, but not larger.

For the Persons with Intellectual Disability and Dyslexia Assocs., text that was easy to understand and well structured with images was very important as well as short sentences, short text lines (max 9.5 cm and unjustified) and extra spacing (1.5 lines). The Dyslexia Assoc. wanted the easy-to-read standard form. Being able to choose paper colour was also desirable.

The Persons with Intellectual Disability Assoc. did not have any need for upper case letters only, but the Aphasia Assoc. did.

The Rheumatism Assoc. preferred standard envelopes to ones with perforated edges.

Having copies sent to another person was a very desirable function for most organisations and the same for the reminding functionality. The Persons with Intellectual Disability Assoc. wanted to be reminded by SMS several times before an appointment: the day before, the morning of the same day and about one hour before the appointment just when it was time to leave home.

The Rheumatism Assoc. wanted to store information about the need for a warm examination room, while the Visually Impaired Assoc. wanted to store information about the need for a very bright or dark room.

Being able to choose information alternatives not yet implemented was not considered a problem for any of the interviewed persons. They were happy to help the healthcare organisation improve their systems.

If adopted, the flexibility of this model would enable Region Skåne to speed up the process of digitising appointment notices for most citizens because non-computerised citizens could still choose to receiving appointment notices on paper.

Conclusion

In this paper I have presented a model for adapting information automatically to each individual's preferences and for facilitating an innovative process where a healthcare organisation and citizens work together.

The proposed model enables individual citizens to take active roles in improving their own accessibility and not just be passive victims of a non-inclusive healthcare information system.

The model is not yet implemented in Region Skåne's information system, but there are technical possibilities to do it next time Region Skåne replaces one of its old information systems for appointment notices. A prototype web form for entering individual preferences has been developed and evaluated and the people interviewed from disability and elderly organisations are eager to have this model implemented.

The web service 'My Healthcare Contacts' is very suitable to include the proposed web form to enable citizens to enter their personal preferences on how they would like to receive information from the healthcare organisation, and what they want the healthcare organisation to know to prepare for a high accessibility of the appointment or treatment

they are called to. Well informed and prepared patients will improve healthcare efficiency and cost effectiveness.

Acknowledgements

References

[1] **World Wide Web Consortium (W3C)** (2008). Web Content Accessibility Guidelines (WCAG) 2.0: W3C Recommendation 11 December 2008
http://www.w3.org/TR/WCAG20/

[2] **Gregor, P, Newell, AF, Zajicek, M** (2002). Designing for Dynamic Diversity: interfaces for older people. In Proceedings of the fifth International ACM Conference on Assistive Technologies (ASSETS 2002), Edinburgh, Scotland, pp. 151-156
http://portal.acm.org/citation.cfm?id=638249.638277

[3] **Ringbauer, B, Peissner, M and Gemou, M** (2007). From "Design for All" Towards "Design for one" – A Modular User Interface Approach.
In C. Stephanidis (Ed.): Universal Access in HCI, Part I, HCII 2007, LNCS 4554, pp. 517-526. Berlin Heidelberg: Springer-Verlag
http://www.springerlink.com/content/v92g252013l1162n/

[4] **Anderberg, P** (2006). FACE: Disabled People, Technology and Internet.
Doctoral Thesis. Lund, Sweden: Certec, Lund University
http://www.english.certec.lth.se/doc/face/

[5] **Nilsson, J** (2008). Utebliven patient dyr för vården. Dagens medicin 2008-02-13 (in Swedish)
http://www.dagensmedicin.se/nyheter/2008/02/13/utebliven-patient-dyr-for-/index.xml

[6] **Mina vårdkontakter** (My Healthcare Contacts). A personal healthcare web service in Sweden
http://www.minavardkontakter.se/

[7] **JotForm**. A web application for developing web forms
http://www.jotform.com/