Citizen Personas: Exploring Challenges of Citizen-Centric eHealth

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Abstract. Within the field of eHealth, there is a shift towards a patient perspective. However, the focus on the patient often fails to acknowledge and achieve a citizen-centric perspective because there is a lack of understanding of the context and complexities of the person and her relations, interests and activities. In this paper we use the persona of ‘Citizen Hanne’ for two purposes. Firstly, to highlight and provide detail in the understanding of the citizen perspective and thereby facilitate a shift towards a citizen-centric perspective, which is advanced by many in the field of eHealth. Secondly, we want to further nourish a critical goal of highlighting the challenges in doing citizen-centric eHealth and pointing out the barriers for reaching this goal.

Keywords. eHealth, Public Participation, Patient Participation, Empowerment, Democracy, Community-Based Participatory Research, Computer Systems Development.

Introduction

What is citizen-centric e-health? The focus within health informatics has primarily been on sharing data among healthcare professionals. This area has been developing steadily in Denmark with national databases that also are accessible for the citizens. However, recent years have seen a need for considering a different kind of data and sharing of information regarding weaker patient groups who are the most frequent users of the healthcare system both in their relations to the primary, secondary and private health care and service sectors.

With the increased focus on telemedicine and patient participation the focus within the field of health informatics has somewhat shifted from a healthcare professionals perspective on eHealth towards a perspective focusing on patient involvement and empowerment. However, in most development projects the healthcare professionals are still the focal point, and implementation of a patient-centric perspective is often scarce and late in the process. Ideas and perceived benefits often take their departure in the point of view of the healthcare professionals and their applications for funding.

Many projects involve the patients as potential users. Telemedicine and care involves the dream of letting patients get treatment in their own homes, thereby reducing costs of hospitalization [1]. However, the shift in focus towards the patient does not necessarily lead to patient empowerment or a citizen-centric approach. The patient provides input to the healthcare professionals through a range of devices, but

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integrated care and the needs of the patient and her relatives are often not fully considered or understood, in their own right.

Other projects have their starting point in technological possibilities and ideas for empowering the patient [2]. Here user involvement and thereby involvement of patient and relatives is often at the centre stage inspired by information systems development methodologies and participatory design [3]. These approaches have gained acceptance within health informatics in recent years where participatory approaches have been used for eHealth development [4][5]. But as mentioned user involvement does not necessarily mean citizen-centric eHealth or democratic ‘design for all’, projects are often designed and address problems for ‘people like us’ [6][7]. The citizen-centric perspective has been proposed at MEDINFO 2013 with the ‘Citizen Mary’ persona and the Village of the future workshops [8]. Questions about how we can create eHealth with the citizen at the centre were raised. In the following sections we explore one perspective that can assist in the understanding of the citizen-centric approach and provide an understanding of the challenges that must be considered in the move towards this approach to eHealth.

1. Methods

The results presented in this paper are based on cooperation between two research groups who have been working within the field of health informatics for more than 20 years. The paper is a result of a joined acknowledgement of the problems of integrating healthcare services and data that have been prevalent in recent years. It is based on a qualitative case study of three elderly people living at home with extensive need of health care services and the input of three relatives to the elderly. All cases are from the region of North Denmark. We create a persona – aggregated description of a person and their point of view also used in the Village of the future workshops [8][9]. The persona is used to highlight the challenges and perspective of citizen-centric eHealth that is often missing in eHealth projects.

2. Results: Persona – Citizen Hanne

Citizen Hanne belongs to the group of physically weak and vulnerable elders living in their own home with multiple chronic diseases and other health problems. Her friends and family support her, but caretakers and nurses from the municipality also assist her in her every day life. The GP is responsible for her health, but she seldom sees her. She has had several admissions to the hospital in the last couple of years and also attends an out patient clinic.

In her everyday life she needs attention and support from physicians, specialists and receives the maximum amount of home-care visits – which is 6 times a day. Sometimes, however, her family and friends take over and assist her with the daily challenges. In addition to homecare, nurses, GP, the hospital and out patient clinics she also has interaction with dentists, physiotherapists, pharmacy, cleaning staff, hairdresser, food delivery staff and other service providers that assist her.

It is a challenge for Citizen Hanne and her relatives to do the necessary coordination between healthcare services across sectors and other service providers. As mentioned above, coordination from the patient perspective involves many healthcare
and service providers from the primary, secondary and private sectors. The different services are separate organizations with their own specialized healthcare information system and procedures. These conditions and the general challenge of coordination between different organizations makes communication, coordination and sharing of information between them difficult and often it does not happen.

The complexity of cooperating, sharing information and communicating in relation to the healthcare and other services raises a range of problems for Citizen Hanne and her relatives. Citizen Hanne and her relatives faces numerous challenges in her interactions with the many service providers, and in her contact with the healthcare system and professionals. The three challenge areas of 1) information sharing, 2) coordination and 3) communication are exemplified below:

Ad 1) When her relatives come to visit her, Citizen Hanne wants to share the latest information about her condition and changes in her care and other services that different providers might have provided and made. However, she forgets what has been said and cannot repeat the information precisely to her relatives. She tries to write important information down, but misunderstandings often happen when passing important information on to her relatives. The problem for Citizen Hanne and her relatives lies in having access to the information that the healthcare professionals and other service providers have about Citizen Hanne and any changes they may make to the care and services she receives.

Ad 2) Three examples of coordination challenges are provided here. One example is when scheduled visits from the healthcare professionals are postponed. She has experienced lying in her bed for 13 hours, because no one was there to help her out of bed - a situation where her relatives could have assisted if they had known. A second example is when her relatives or friends want to take Citizen Hanne on a trip or for a visit outside her home. They then call the healthcare service providers to cancel scheduled visits. However, the information gets lost and the healthcare professional come in vain to the canceled care visit. In the third example Citizen Hanne experienced that a stranger turned up at her door and claimed to be from the healthcare services, but how could she be sure? She rejected the stranger and did not get the help she needed. The three examples point towards problems relating to coordination and communication that citizens can face in their relations to healthcare and service providers. The problems for Citizen Hanne and her relatives are the lack of coordination and information sharing about time schedules and changes from both the perspective of the healthcare professionals and citizens e.g. information to the client and her relatives about time schedules and information about who will be on duty to take care of Citizen Hanne in her home.

Ad 3) Citizen Hanne regularly needs to have her type 2 diabetes medicine adjusted. This is done at the GP. However the GP expects their clients to take contact when regular checkups are due. This might not be a problem for most clients, but Citizen Hanne and her relatives can easily forget this when challenged by all the other appointments they need to manage. The healthcare information systems and practices of the GP simply do not support the communication needs of Citizen Hanne and her relatives.

There are numerous other examples of the challenges that people in Citizen Hanne’s situation and their relatives face in their every day lives. These challenges highlight the fact that the elderly Citizen Hanne and her relatives cannot navigate in the complicated arena of coordination, communication and information from hospital visits and practitioners, schedules for home-nurse, care and cleaning visits etc. The persona
presented here is of course not fully developed, but it nonetheless showcases some of the depth you can achieve when using this perspective. This persona also highlights the challenges of a specific group of elderly with relatives that assist in the care. Different personas are needed for different kinds of elderly, for example those without assistance from relatives, those with smaller health issues who might need assistance for staying healthy etc. For the purpose of this paper, we use the persona of Citizen Hanne in the following section to create a citizen-centric focus in eHealth and highlight challenges from this perspective.

2.1. Challenges when putting the citizen in the center of concern

We use the persona to highlights some interesting pitfalls in developing citizen-centric eHealth. In the following these are categorized through the challenges found by Moen et al. [10] in “eHealth in Europe – Status and Challenges” namely ‘strategy and policy’, ‘organizational’, ‘professional’ and ‘technological’. The point of view of their study is, however, not citizen-centric but originates from IT and healthcare professionals working within the field of eHealth. Using the persona as point of departure we present how healthcare is perceived and what challenges arise from the point of view of Citizen Hanne. Healthcare providers and support networks are placed in a Venn diagram in relation to their role from the citizen perspective while challenges identified by Moen et al. are presented in transverse categories and related to the citizens perspective.

![Figure 1](image-url)  
Figure 1. A Venn diagram exemplifying the citizen-centric point of view on healthcare for the persona Citizen Hanne and the challenges of eHealth in meeting the demands of this perspective (the four categories).

In relation to ‘Policy and Strategy’, the persona highlights the before mentioned fact that healthcare information systems often are made by and for healthcare professionals. The link to the citizen – in a language and form that the citizen understands - is still underdeveloped. Funding for projects mainly goes through the healthcare organizations or development of specific technologies for healthcare management. The focus on efficiency and lowering costs in eHealth projects also hinder the citizen perspective on quality of care. Lastly legislations on data privacy hinder sharing information across sectors and with relatives and friends.

When it comes to the organizational challenges the problem of communication and sharing information between healthcare professionals prevail in relation to the citizen’s
perspective. There are no easy solutions in relations to gaining shared understanding in communication and sharing data across different professional and citizens perspectives.

If we consider the professional challenges the need for a holistic perspective on patients is a central issue. It is not only necessary to think across sectorial borders, but also to understand the patient’s perspective and needs for information from their point of view. Further there is a problem of communicating in a language that the citizens understands when seeking information through the healthcare information systems.

Lastly the technological challenges are a key issue is providing better means of data sharing and information infrastructure. Politically and organizationally there is a need for easy access to data from all the different information systems used in healthcare. However the focus on data is not enough. In a citizen-centric perspective the eHealth technologies needs to be designed for and with the citizens, not just as users, but also as key stakeholders. eHealth technologies are not just clinical systems. From a citizen perspective it involves technologies that support them in sharing information, communicating and coordinating in their everyday lives.

3. Discussion: Towards citizen-centric eHealth

Through the persona we highlight key issues that need to be addressed in order to achieve citizen-centric healthcare and eHealth. We also illustrate how personas can be used for gaining a more nuanced understanding of the citizen’s perspective on eHealth. In order to move forward towards citizen-centric eHealth development we must consider the challenges, but also change the focus of the eHealth projects from the healthcare professionals point of view towards the citizens in order to create a basis for the involvement or empowerment that many eHealth professionals claim to aim at. In order to reach this goal more projects need to focus on developing a detailed picture of the citizen’s perspective and the ways the everyday lives of citizens can be supported by eHealth design and development – from the point of view of the citizen.

References