



Journal of Assistive Technologies

Scripting the active patient in online health communities

Femke D. Vennik Samantha A. Adams Kim Putters

Article information:

To cite this document:

Femke D. Vennik Samantha A. Adams Kim Putters , (2015), "Scripting the active patient in online health communities", Journal of Assistive Technologies, Vol. 9 Iss 2 pp. 86 - 99

Permanent link to this document:

<http://dx.doi.org/10.1108/JAT-10-2014-0023>

Downloaded on: 09 November 2016, At: 20:45 (PT)

References: this document contains references to 39 other documents.

To copy this document: permissions@emeraldinsight.com

The fulltext of this document has been downloaded 34 times since 2015*

Users who downloaded this article also downloaded:

(2015), "The development of safer walking technology: a review", Journal of Assistive Technologies, Vol. 9 Iss 2 pp. 100-115
<http://dx.doi.org/10.1108/JAT-07-2014-0017>

(2015), "Haptic-audio simulator for visually impaired indoor exploration", Journal of Assistive Technologies, Vol. 9 Iss 2 pp. 71-85
<http://dx.doi.org/10.1108/JAT-06-2014-0016>

Access to this document was granted through an Emerald subscription provided by emerald-srm:563821 []

For Authors

If you would like to write for this, or any other Emerald publication, then please use our Emerald for Authors service information about how to choose which publication to write for and submission guidelines are available for all. Please visit www.emeraldinsight.com/authors for more information.

About Emerald www.emeraldinsight.com

Emerald is a global publisher linking research and practice to the benefit of society. The company manages a portfolio of more than 290 journals and over 2,350 books and book series volumes, as well as providing an extensive range of online products and additional customer resources and services.

Emerald is both COUNTER 4 and TRANSFER compliant. The organization is a partner of the Committee on Publication Ethics (COPE) and also works with Portico and the LOCKSS initiative for digital archive preservation.

*Related content and download information correct at time of download.

Scripting the active patient in online health communities

Femke D. Vennik, Samantha A. Adams and Kim Putters

Femke D. Vennik is a PhD Student at the Institute of Health Policy & Management, Erasmus University Rotterdam, Rotterdam, The Netherlands. Samantha A. Adams is Assistant Professor at the Tilburg Institute for Law, Technology, and Society, Tilburg University, Tilburg, The Netherlands. Kim Putters is Professor at the Institute of Health Policy & Management, Erasmus University Rotterdam, Rotterdam, The Netherlands.

Received 24 October 2014
Revised 15 December 2014
Accepted 22 December 2014

Funding of this research was provided by MijnZorgnet. The role of the funder in the research process was limited to providing financial support. The authors wish to thank all employees who worked at MijnZorgnet for the opportunity to study their daily activities and for sharing their thoughts and experiences. In addition the authors would like to thank all of the interviewees for taking the time to talk to the authors and for providing them with interesting and relevant information. This paper has further benefited from the comments of colleagues and the authors especially like to thank Lieke Oldenhof and Hester van de Bovenkamp for their contributions.

Abstract

Purpose – The purpose of this paper is to improve the general operationalization of an “active patient,” by examining the specific activities and skills expected of active patients.

Design/methodology/approach – Expected activities and necessary skills were studied through a qualitative case study into the development and use of an assistive technology (i.e. web site) aimed at stimulating active patient-ship. Interviews, observations and document analysis were used to capture and explore designers’ inscribing practices and their consequences regarding expected competences and activities of patients using the web site.

Findings – Designers inscribed two “co-design roles” that active patients were expected to perform on the web site (co-designing their own healthcare and co-designing the healthcare of peers), for which at least eight different competencies were needed. The absence of skills or facilities to apply these skills resulted in incomplete use, a different use than intended by designers and non-use of the web site.

Practical implications – Technological choices and inscribing processes determine who is able or facilitated to become active and who is not. Due to inscribed co-design roles, it also influences the extent to which already active peers are able to perform health-related activities. Different users with different conditions should be taken into account in the design as specific group characteristics can influence level of individual activity.

Originality/value – This study is, as far as the authors know, the first that examines the “active patient” concept by studying an assistive technology and using scripting literature, resulting in an improved understanding of what it means to become “active” in terms of skills and activities.

Keywords Healthcare, Co-design, Active patient, Patient participation, Scripting, Technological design

Paper type Technical paper

Introduction

“Passive patients are patients of the past; active patients are the present and future.” This – somewhat provocative and sharply phrased – notion can currently be found in many policy documents and literature on patient participation (Van de Bovenkamp, 2010). While “active patient-ship” applies especially to the involvement of patients in their own health and healthcare, it also applies to other levels, for example participation in improving the quality of hospital care (see, e.g. Vennik *et al.*, forthcoming). Because information and communication technologies (ICT) are seen as enabling instruments that facilitate patients’ personal health-related activities (Anderson *et al.*, 2003; Eysenbach, 2008; Czaja *et al.*, 2013), expectations for their contribution to active patient-ship are high. They are expected, for example, to help patients integrate large amounts of complex health information (Baker *et al.*, 2010) and enable self-care (Harris *et al.*, 2010). In recent years, ICT applications that help patients undertake activities that support their own health and care, here further described as patient-oriented ICT applications, have been developed.

Though there is much literature on patients’ transformations from passive to active and the stimulating role that ICT could play, this rarely makes explicit what is meant by this changed

concept of the patient. What are “active” patients, or what should they be? What skills do they need, for example, in order to use patient-oriented ICT applications? And is it, for instance, possible to be active in the “wrong” way? Until now, the description of active patient-ship has been limited to “managing your own healthcare” (Henkemans *et al.*, 2010), “gathering information to be informed about diseases and treatments” (Anderson *et al.*, 2003; Crawford, 2006; Henwood *et al.*, 2003), “participating in medical decision making” (Lee *et al.*, 2010) and “taking up a healthy lifestyle” (Van de Bovenkamp, 2010). Such operationalization gives a general description of activities but remains largely rhetorical (Schermer, 2009), as the specific tasks and skills these activities comprise – and the consequences of (not) possessing/utilizing these skills – remain unclear.

To learn more about the content of the word “active,” this paper focusses on the development of a patient-oriented ICT application. Technologies are not neutral tools; they carry various inscriptions of the developers and designers (Akrich, 1992; Oudshoorn *et al.*, 2004). For example, the materials used to build cars reflect predictions of the developer and designer about the stresses cars will have to bear (Akrich, 1992). By studying these materials, it is possible to explore and explicate designers’ specific ideas and notions of (future) users. Applied in this context, examining the development and design of an ICT application, reveals expectations for the (future) active patient, demonstrating which preferences, competencies and activities are inscribed by designers in the technical product (Oudshoorn *et al.*, 2004). The result of the inscribed users’ representations in technologies is called a “script” (Akrich, 1992, p. 208).

In this paper, we aim to examine the “active patient” concept further, by studying how designers’ expectations regarding patients’ competences and activities are reflected and scripted in patient-oriented ICT applications. The research question guiding this paper is:

RQ1. How is the “active patient” scripted in the design of a patient-oriented ICT application?

Insight into this question is scientifically and practically important as it explicates professionals’ and policy-makers’ expectations of patients’ skills and activities and it results in an improved conceptualization of what is currently expected from patients (Boivin, 2012). This will sharpen the scientific and policy debate of active patient-ship.

This paper begins with a brief overview of active patient-ship literature. This is followed by an explanation of the scripting concept and how it is relevant to this case. In the methods section we describe the research design, and in the results section we illustrate the scripting activities that took place in the development of a patient-oriented ICT application. In the discussion and conclusion we reflect on the consequences of these scripting activities, in light of the “active patient” concept.

Active patient-ship

The involvement of patients in their own health and healthcare has always been a social practice. However, through the years, different institutions and developments have influenced the extent to which patients have been stimulated to become “more” or “less” active. Steele *et al.* (1987) provide an overview of the active patient concept starting from the mid-eighteenth century. At that time, writers stressed the search for self-help alternatives due to broad societal interest in personal freedom, autonomy and personal responsibility combined with a growing distrust of medical authority. These ideas flourished into the nineteenth century but became less discernible when, among other things, major advances in medical technology were realized (e.g. the discovery of X-rays), along with new ways to treat and prevent diseases (e.g. with improved vaccines). This resulted in increased medical authority at the beginning of the twentieth century (Steele *et al.*, 1987). This increase, however, did not last long; professional authority was again challenged in the second half of the twentieth century when socio-political critiques “called for more egalitarian power-sharing within the clinical consultation,” to move away from paternalistic physician-patient relationships (Boivin, 2012, p. 10) where doctors govern and decide. In this period, patients’ rights such as “informed consent” and the right to participate in decisions concerning their own health were introduced (Steele *et al.*, 1987). According to Van de Bovenkamp (2010), these rights strengthen the position of patients. At the same time, they also (legally) place emphasis on a more active patient, who makes individual health choices or decisions together with healthcare professionals and manages his/her own health (Boivin, 2012).

Besides the more democratic argument, that patients have the right to be involved in decisions concerning their lives, there are also other arguments for stimulating an active patient and to move the boundaries of patient skills and initiatives, such as to enhance the legitimization and quality of decisions (Van de Bovenkamp, 2010). Moreover, active patient involvement could, for example, potentially lead to improved dialogue during medical consultations, as patients give opinions and ask questions, resulting in a more complete information exchange and ultimately improving the quality of care (Steele *et al.*, 1987). Finally, stimulating patients to become active and do more themselves could control costs by reducing the burden on health systems; an important argument at a time when healthcare costs continue to rise and the chronically ill population continues to grow. These arguments illustrate that there are multiple reasons for not being excused from an active role in society when one is ill.

Professionals and policy makers anticipate that not every patient is able to become more active on his/her own and search for ways to support patients in assuming a more active role. In this respect, much is expected from ICT applications, which are seen as important instruments to facilitate patients in health-related activities (Adams and De Bont, 2007). Technological developments in this area, such as the availability and accessibility of health information through the web, have stimulated more (intense) possibilities for patients to become active, possibly leading to other tasks and responsibilities of patients, as well (Hardey, 1999).

Scripting users in technologies

To gain a better notion of the “active patient” concept, it is particularly suited to study healthcare-related technological developments aimed at involving patients in their own health and healthcare, as studying these technologies makes it possible to distill designers’ inscribed vision of the skills, behavior and activities of (future) users of the technology. Designers have a specific configuration of the user in mind (Akrich, 1992), which determines how they shape the technology of a product in terms of materiality, layout, functionalities, etc. By studying design practices and thus by looking at these different aspects, the user configuration becomes explicit, which makes it possible to deepen our understanding of what it means to be(come) an “active” patient.

A study by Oudshoorn *et al.* (2004) illustrates that designers’ “inscribing” processes – i.e. the translation of the designers’ vision of the competencies, actions and responsibilities of the user into the design (Akrich, 1992, p. 208) – are influenced by both the environment in which they find themselves (“macro dynamics”) and their own personality (“micro dynamics”), and that these dynamics influence the inclusion and exclusion of users. Regarding the macro dynamics, they showed, for example, that the initial wish of designers in their study to include a diversity of users gradually became overruled by a more marketing-related focus of having an innovative product. To be “innovative,” this study showed, meant not lagging behind in using the latest computer software programs. Because this software was not accessible to every user, specific (types of) users were excluded. This illustrates that when differences between users are not taken into account, certain competences and wishes of specific segments of the populations are excluded, making it impossible to design for “everybody” (Oudshoorn *et al.*, 2004). When designing a patient-oriented ICT application, the diversity in patients groups should thus be taken into account, which means avoiding categories of users that are too broadly defined (Van Loon *et al.*, 2014).

The inclusion and exclusion of users is also influenced by micro dynamics, specifically by the use of the “I-methodology” (Akrich, 1995): a concept referring to designers’ tendency to take their own “preferences and skills as major guides in the design” (Oudshoorn *et al.*, 2004, p. 53). Applying I-methodology can lead to an overestimation of the skill set of the more “average” user. Consequently, this further contributes to the inclusion and exclusion of specific users. In addition, taking the self as a representative model could result in the exclusion of users based on certain aspects, such as gender: the work of predominantly male designers may lead to a masculine design style, primarily attractive to, and thus used by, men (Oudshoorn *et al.*, 2004; Rommes *et al.*, 2011). Though many studies explore so called gender-scripts (e.g. Ravneberg, 2012; Shade, 2007; Van Oost, 2003), similar studies on scripted roles of “active” patients were not found in the literature.

Although design influences the inclusion and exclusion of users and is able to govern user behavior, for example by technically stimulating or limiting certain (inter)actions, it does not mean that users are passively submitted to a certain script (a view also known as technological determinism) (Akrich, 1992; Oudshoorn and Pinch, 2003). Contrary to a more linear notion of technological innovation where the agency of designers is placed above that of users, users can better be viewed as co-designers who “may slightly modify the scripts, they may drastically transform them, or they may even completely reject them and create new meanings and uses of the objects or become nonusers” (Oudshoorn and Pinch, 2003; Oudshoorn *et al.*, 2004, p. 55). Examples of such modified scripts are ICT applications that are used in a different way or for a different purpose than intended by designers. Scripts could thus reinforce existing user behavior but could also create new behavior. It is therefore possible that users (and technologies) take on different roles in practice than what the designers had envisioned.

Given the above, it is important to look at design practices in their entirety when studying inscribing processes and scripts related to the active patient. This means that it is not only vital to focus on the design of a product, but also to take into account the broader context in which the product is (being) built. Additionally, not only designers’ points of view have to be taken into account, but also the view of users of the technological product (Akrich, 1992). These views should be alternated continuously, to fully understand how a behavioral architecture (i.e. the technological design that stimulates certain user behavior) is actually inscribed and (co-)created by both designers and users.

Methods

Case study

To explore how the “active patient” is scripted in the design of a patient-oriented ICT application, an in-depth qualitative case study was performed into MijnZorgnet (“my health net”). This was a Dutch organization engaged in building an assistive technology: the patient-oriented web site (www.MijnZorgnet.nl). This web site was a web-based community platform where patients and physicians could communicate and exchange knowledge. When the organization started (2009), the idea of MijnZorgnet was proclaimed by the Minister of Health, Welfare and Sports (VWS) to be a pioneering healthcare initiative; the initiative received four-year funding from VWS and the Radboud University Medical Centre. It was initiated by two healthcare professionals who wanted to increase opportunities for patients to actively participate in their own healthcare processes, to stimulate better collaboration between physicians and between physicians and patients, and to change the current healthcare system into a more patient-centered system (Faber *et al.*, 2012). The past tense is used because the organization and web site under study no longer exist in the researched format. To be clear, the aim of this paper is not to provide an explanation for this ending. This paper aims to examine the “active patient” concept, by studying how designers’ expectations regarding patients’ competences and activities are reflected and scripted in patient-oriented ICT applications.

As described above, studying inscribing processes meant studying MijnZorgnet from a broad perspective. We included both the design of the product and the context in which it was being built into the study. In addition, as recommended by Akrich (1992), we continuously alternated between the organization MijnZorgnet, the web site they were building, and end users (i.e. patients), using a variety of data collection methods: observations, document analysis and interviews.

Observations

The main research method used in this study was observation. Observations were conducted by the first author during weekly meetings held by MijnZorgnet’s team between November 2010 (when the web site was launched) and August 2012 (when the organization stopped in its current structure by a shortage of financial resources). MijnZorgnet’s team consisted of approximately 14 employees (male and female), each focussed on a different aspect related to

the web site: technological development, product and support, marketing and sales, research and business management. Examples of observed meetings are:

- “The round”: morning rounds at the end of every week in which each employee recited the activities he/she had performed that week.
- “Deliverable of the month”: sessions in which employees presented the achievements and activities of that month.
- “Colloquia”: sessions once a week in which employees or external guests gave presentations on certain topics related to the organization’s work.

During these meetings, current and future (technological) developments regarding the web site and organization were discussed, under the leadership of two directors (the healthcare professionals who started the initiative). Every employee was free to voice his/her opinion regarding this development process.

During the observations, the researcher was primarily focussed on speech (e.g. what was said), visual aspects (e.g. facial expressions) and the activities performed (e.g. adjustments to the web site). In addition, during observation moments, informal interviews with employees of MijnZorgnet were conducted. The observations and informal interviews provided insight into how MijnZorgnet employees wanted to design the patient-oriented web site, their views of patients (i.e. their roles, skills, etc.), and how they thought that patients should use the web site.

During all observations, extensive field notes were taken and worked out into thick descriptions. The field notes were divided into descriptive notes, reflective notes (i.e. personal thoughts) and demographic information such as time and place of the observations (Creswell, 2003). Some observations were recorded with permission and transcribed verbatim. During the observations, the employees knew that the researcher was present to collect data.

Document analysis

In addition to observations, relevant “documents” (in the broadest sense of the word) were analyzed by the first author. Examples are PowerPoint presentations given by MijnZorgnet staff, strategy documents compiled by the organizations’ Board of Directors and the web site that was being built. Regarding the latter, different aspects of the web site were observed and analyzed, including the layout, the login, the available (instruction) information and the help desk. Specific attention was paid to designers’ language use and the usability of the site. To gain more in-depth knowledge of how the web site was used by patients, five online health communities on the web site, accessible for anyone with internet access, were observed for eight to 21 months (between December 2010 and September 2012). See Vennik *et al.* (2014) for a detailed description of the selection of these communities. Discussion themes of these communities included Parkinson’s disease, cerebrovascular accident and fertility care, and the communities consisted of different information and communication functionalities including blogging applications, forums and wikis. The aim of observing the communities was to find out how the different functionalities were used and whether that corresponded to the intentions of the designers, which was possible to compare due to the data obtained by the observations described above. The web site analysis (including patients’ use of the web site) was performed by taking screenshots of the web site and analyzing all the content and visible aspects present while making descriptive and analytic notes (Bernard, 2006).

Interviews

Lastly, the first author performed semi-structured interviews with MijnZorgnet employees and web site users (i.e. patients). Interviews were held with a selection of MijnZorgnet staff ($n = 5$) (i.e. one director, project coordinator, marketing and sales employee, implementer and a process manager support and technology). The selected key persons were interviewed to deepen and validate some more general findings of the observations and document analysis. During the interviews, staff members were invited to talk about the development of the organization and web site, their own role, their vision on the web site and on the patients’ role. The interviews were conducted face-to-face at the organization MijnZorgnet and lasted approximately one hour each.

Semi-structured interviews with users of two of the five observed online communities were also conducted ($n = 17$). The two communities, about Parkinson's disease, were selected because they had the longest life span of the five observed communities and a relatively high number of members, which increased the possibility of activities and postings within these communities, giving a clearer picture of how the communities were used. Additionally, the users of these communities – chronically ill patients under age 50 – were according to the directors of MijnZorgnet the ideal target group of MijnZorgnet.nl. The users (nine male, eight female; between the ages of 39 and 65; time since diagnosis of Parkinson's disease ranged between one and 18 years) were contacted through forum and private messages, with permission from the community managers. During the interviews they were asked to explicate their experiences with the web site and were invited to talk about why, how and when they used the web site. With the exception of four telephone interviews, the interviews were conducted face-to-face at the respondents' houses and lasted 73 minutes on average.

Data analysis

The interviews were tape-recorded with permission and transcribed verbatim. All transcripts, field notes and documents were analyzed qualitatively. First, all data were carefully read and data related to the role and activities of patients were selected and labeled. Second, labels that shared a commonality, for instance activities that an active patient needed to perform, were clustered and formed into categories. As a final step, themes were created by selecting the core category (i.e. active patient) and to link this category to the other categories (i.e. aim of MijnZorgnet, expectations of patients using the web site and experiences of patients with this web site) (Creswell, 2003). This process of analysis continued until no new codes, categories and themes emerged (Bowling, 2002) and was performed by the first author and checked for consistency of application of the codes to the data by the second author.

Ethical considerations

Permission to perform the interviews with employees and the observations at the organization was given by the directors of MijnZorgnet. In addition, permission was obtained from the Committee on Research Involving Human Subjects (in Dutch: Commissie Mensgebonden Onderzoek Regio Arnhem-Nijmegen) to interview users of MijnZorgnet.nl. The content of this web site was available for scientific research as a result of the user agreement. To respect the privacy of the participants in this study, pseudonyms are used (Creswell, 2003).

Results

In this section, we first describe the healthcare changes that the staff of MijnZorgnet had in mind and illustrate how they wanted to reach this envisioned change, by introducing MijnZorgnet.nl. Then, we describe which skills the organization expected patients to have/develop and how these translated into specific activities on the web site. Finally, we discuss patients' experiences with the web site and compare these experiences with the designers' vision, to illustrate the consequences of scripting activities.

Changing healthcare by patients using online communities

MijnZorgnet was an organization aimed at changing the current healthcare system into a more patient-centered system, by stimulating personalized care and reducing fragmentation of care. Building a patient-oriented web site (i.e. MijnZorgnet.nl) with the technological design of online health communities facilitated by communication functionalities such as blog, wiki, forum and the option to exchange files, was seen as a way to reach this goal. The underlying idea was that by using different types of online communities, illustrated in the list below[1], in which patients have an "active" role (see the following section for an elaboration on what this "active" precisely means), the health network of the individual patient becomes transparent, which could stimulate (improved) collaboration and communication between healthcare professionals and between professionals and patients, thereby reducing fragmentation of care. Additionally, the

health network could provide access to relevant (personal) health information leading to better-informed patients.

Community types on MijnZorgnet.nl:

1. Personal health community (PHC):
 - content is only visible for community members; and
 - community of one person who is surrounded by his/her physicians and other relevant actors to his/her health (see also Aarts *et al.*, 2014).
2. Private hospital community:
 - content is only visible for community members; and
 - patients and physicians of a specific hospital ward are gathered.
3. Public general community:
 - content is visible for everyone with internet access; and
 - patients and physicians that generally do not know each other are gathered (see also Vennik *et al.*, 2014).
4. Private general community:
 - content is only visible for community members; and
 - patients and physicians that generally do not know each other are gathered.

The choice for the type of web site was motivated by the positive experience of one of the directors with the use of online communities in healthcare. However, making this choice also shaped the first user representation: the user was configured as someone with access to a computer and working internet connection. At that time, this meant almost everyone in the Netherlands (European Commission, 2014). This was in line with the target group MijnZorgnet envisioned: “every Dutch citizen” could create a profile on MijnZorgnet.nl, after which he/she could focus on his/her own health by participating in different health communities (see the list above). They configured the user thus as “everybody.” Within this group of “everybody” they expected particularly most activity and enthusiasm from chronically ill patients under age 50 (observation March 18, 2011).

Scripted expectations of active patients in online communities

Every patient was expected to be able to and actually use the web site, because, “From the beginning we [of MijnZorgnet] created something that is generically available for anyone” (Director 1). One of the community types on the web site was the PHC and patients were expected to use this community in the following way:

Here [in the PHC] the patient creates his own team of healthcare professionals or even loved ones, family, children, people who are involved in your care; you can organize and decide it yourself. This creates a personal community in which the patient is in the lead and this way you give others access to all sorts of information about your healthcare, that provides them with insight, and they can also add information. Well, the ultimate goal of this is of course shorter lines, no fragmentation and patient-centeredness (Product manager, transcribed observation January 21, 2011).

The PHC contains the notion that “transparency” is a necessary precondition to improving communication and coordination in care, whereby it refers to the visibility of individuals involved in a patients’ care process and the information they can contribute. These individuals include physicians but also other relevant actors in the patients’ social network such as family members, and must have access to the same online space (a PHC) where they can “gather” and where all relevant data are stored. Coupled on this, MijnZorgnet gave individual patients the responsibility to manage this space by selecting and inviting relevant people in their network and by controlling

the content of the community. With this, the reframing of the patient as having a more active role in healthcare becomes apparent. It illustrates that patients, in partnership with healthcare professionals, family members and/or (patient) peers, become (more) integrally bound up in care-related activities, thereby “co-designing” their own healthcare.

The envisioned active co-design role was, however, not limited to the PHC, it applied to all community types on the web site. In private hospital communities and general communities, patients were, for instance, expected to gather information (e.g. about treatment options) by searching for relevant content and posing questions to physicians and peers. In addition, patients were expected to provide meaningful and transparent information to help (unknown) others (e.g. about coping strategies). Patients were thus also asked to co-design other patients' health, by becoming (more) integrally bound up in activities related to the care of others.

These two scripted co-design roles required specific skills and competences, which became visible by looking at the design of the web site. For example, the activity “gathering information (e.g. about Parkinson's disease), by searching on the website for relevant content and posing questions to physicians and peers,” meant that patients first had to have Dutch reading and writing skills, as this was the main language used on the web site. In addition, as some applications on the web site (such as “community” or “blog”) were referred to in English, patients also needed to have some understanding of the English language and what these terms mean with respect to the functionality of those sections of the site. Furthermore, finding relevant information on Parkinson's disease required using the web site's search and, by default, typing relevant search terms. In the search process, patients saw a list of information available on the web site related to these terms (the more information, the longer the list and anything on the web site could “pop-up” including community themes, physicians working on that specific subject, forum, blog or wiki messages and PDF's). Next it was up to patients to select the relevant item(s) from the list and to evaluate the information in terms of reliability and appropriateness/relevance to their personal health situation. When patients could not find the information they were looking for, questions could be posted within a community, implying that it was first necessary to find the right community. Every user could start a community on the web site and related to Parkinson's disease there was, for instance, a community for young patients with Parkinson's disease (i.e. patients under age 56) and a community for questions about Parkinson's disease and having a job. Patients needed to have found both communities in order to know that work-related questions could best be posted in the latter community, as the former in general concerned the same target group, but did not discuss work-related subjects. Once the right community was selected, it was necessary to find the correct area (e.g. blog or forum theme) within the community to formulate the question.

This example reflects the assumption on the part of MijnZorgnet employees that the user was someone similar to them: predominantly highly educated, young professionals between the ages of 26 and 40; a group familiar with the use of computers and internet, who are able to easily find information and who use social media sites such as Twitter and Facebook where the use of English terms is customary (see the following section for whether or not this corresponded with the actual users). In addition, the example illustrates that “being active” not only means that you have to perform different kind of activities; you also need to have the right (level of) skills to perform these activities. To unravel the “active patient” concept, it is thus not only important to focus on the scripts of activities that users have to perform, it is also necessary to take into account the role descriptions of required skills and competences to perform a script (to remain in the theater metaphor).

Based on the observations, document analysis and interviews, we distinguish at least eight different skills that users should possess: technical computer skills (e.g. to use different functionalities within the online communities); reading and writing skills (i.e. Dutch proficiency and a general understanding of English); intellectual skills (e.g. to formulate a question); information skills (i.e. to search, find, critically analyze and process various sources); reflective skills (e.g. to translate information into the own healthcare context); leadership skills (e.g. to initiate writing information in different types of communities); management skills (e.g. to organize relevant information in the PHC); and relational skills (e.g. to invite physicians in one's PHC). There is an implicit expectation that these skills are already present and that they will automatically flourish

regardless of the context, or that they can be developed in every patient. However, when this is not the case, it means that certain users will be excluded or “scripted-out” of using the web site.

Users' experiences with and consequences of using the web site

Having illustrated designers' expectations regarding active patients, it is time to explore users' experiences with the web site, to see whether these correspond. Interviews with users of the web site have shown that patients indeed experienced benefits using online communities on MijnZorgnet.nl. General communities were, for instance, used to performing medical activities (e.g. to prepare for the consultation with the doctor), emotional activities (e.g. to gain recognition) and lifestyle activities (e.g. reading tips on how to combine working with having a disease) (see Vennik *et al.*, 2014). Regarding the PHCs, potential benefits were identified relating to the organization of care (e.g. better collaboration between physicians) and care experience (e.g. reducing stress) (see Aarts *et al.*, 2014). The extent to which these benefits could be achieved was, however, strongly related to the usability of the web site and thus to the technological design. Some patients experienced difficulties with that.

The majority of users experienced two types of difficulties in particular. The first was navigating the web site. This concerned not only the technology to go from one hypertext link to another on the web site, but also how available information was structured. Some users did not understand where to “click” to see the information they were searching for. Others found it difficult to find the way back to their starting point once they had “clicked through” the web site. Most users found the information inconveniently arranged, for example because of the dissemination of information about a particular subject within various communities (which was possible as every user could create a community and was able to post content wherever he/she wanted). Because of this, navigating to relevant information was no minor issue. The web site designers scripted patients with technical computer and information skills, but users' experiences illustrate that these competences were not adequately present in the actual users or facilitated by the web site.

The second difficulty related to navigation concerned the functionalities for information provision and exchange. The designers had chosen to include different functionalities within the communities, each for a different and distinct purpose. A blog, for instance, was described during one of the observations as a place to “inform every member about something that you, as a community owner, find important,” whereas the forum functioned as “a place for discussion” in which everyone could participate (product manager, transcribed observation January 21, 2011). However, for some users, neither the purpose of the different functionalities, nor how to use them was entirely clear:

All those other terms and “community,” I thought, what should I do with it? Because, well, my English is not so good and then you have all those other terms that you never use in ordinary everyday life (Female user, 65 years).

The man asked “how do I post a message” and I also sometimes have problems with that. Then I think yeah why am I making such an effort? I'm already giving something of myself, so if it takes too much effort I'm done with it (Male user, 60 years).

The interviews revealed that some users did not know the difference between certain functionalities; they experienced them as similar, did not know what they were meant for or how to use them. An instruction on how to use the functionalities was also not immediately visible on the web site. To find this information, users had to go to the help desk for which they first had to register by e-mail address or Twitter account.

For other users the functionalities were (more or less) clear, but they sometimes faced other challenges: they did not know what to post or felt insecure in writing a message. This implies that providing a technological web site is not enough to make a user/patient active on the web site, as they still might not have the right level of skill or face other challenges:

The aim [of a wiki] is clear I guess, working together on a question [...]. But what kind of information should I add and which theme should be selected? That, I wouldn't know (Male user, 47 years).

I find it rather difficult to post something because I'm very dyslexic and then I'm not sure how to write it down. Those [doctors] are so highly educated and then I find it sometimes difficult to ask a question. Even if I want to, it does not mean I'll always do it (Female user, 49 years).

The combination of navigating difficulties, technologically unfamiliar functions and patients not knowing what to add in terms of content or how to write it, resulted in “empty” functionalities within various general communities. Especially content in blogs and wiki’s remained absent for a long period, sometimes permanently. Not all users could meet the inscribed competences of patients, resulting in a non-use of certain aspects of the web site.

Moreover, some users used the web site differently than envisioned by the designers. For example, questions and experiences were posted in unintended places. Accordingly, both patients and designers tried to actively steer users’ actions to ensure that the web site was used in the “proper” way. Users explained, for instance, to one another where to post information, while the organization MijnZorgnet adjusted the technology:

You see that also on MijnZorgnet.nl; someone posts a message and somebody else tells you it’s better to move it. [...] So I guess it is difficult for a lot of people (Female user, 57 years).

The help desk receives different kinds of questions. An employee in control of the help desk says that the new help desk arrangement should stimulate users first to search for solutions themselves, instead of “randomly shooting things into the help desk”. He says that the current contact option is too easy to access and that when it’s removed, questions can be better controlled. One director asks the employee how one can force people to ask less questions. The employee suggests: 1) by making it more difficult to ask questions, 2) by posting a proper frequently asked questions list, and 3) by introducing a help button (Observation, May 27, 2011).

Although asking questions was one of the envisioned elements of the active patient, the observation above illustrates that asking questions about how to use the web site was not what MijnZorgnet was aiming for. This implies being active might be different from what was expected and viewed as a “wrong way” or in a “wrong place.” To stimulate the “right” way and place, in this case to find solutions for problems themselves first on the web site, the technology was adjusted and reshaped by the designers to steer users in a different direction. Prior user behavior contributed to this design change, which illustrates that patients also functioned as co-designers of the web site.

However, it should be noted that being “wrongly” active is not always visible for designers who study user behavior by (solely) observing the use of the technological design. During the interviews, some respondents indicated that they connected with peers on MijnZorgnet.nl (e.g. by using the forum), but that they soon made use of their own e-mail address instead of the web site to exchange experiences with peers. The complicated log in process (by using DigiD, the identification method of the Dutch government to identify internet users) compared to e-mail and the limited time they had on the web site (approximately 15 minutes) before they were automatically logged off due to security reasons, were reasons for users with Parkinson’s disease (who in general have coordination problems) to make this shift. Due to this shift, the premise of transparency and idea that patients could co-design the health of many others were both replaced by co-designing the health of an individual in another web space. An understanding of a different use of the web site than intended could, in this case, only be made visible by interviewing users. In order to steer (and eventually script) user behavior, designers must therefore actively include actual users (instead of proxy users such as professionals, which often occurs) in the development of the web site; MijnZorgnet only included actual users in limited fashion (i.e. in relation to certain developed technological aspects of the web site).

Discussion and conclusion

With this study, we explored how the “active” patient is scripted in the design of a patient-oriented web site. By studying the organization creating the web site, the web site itself and users’ experiences with the site, this study provides in-depth insight in inscribing processes and co-construction of assistive technologies such as information platforms intended to support “active patients.” The results show that designers inscribed two co-design roles that active patients were expected to perform on the web site: co-designing own healthcare and co-designing the healthcare of other patients. To perform these roles, patients needed to have at least eight different competencies, including technical computer skills and information skills. The consequences of these inscriptions will be further discussed in this section.

We illustrated that the target group of MijnZorgnet.nl was every Dutch citizen (with specific expectations regarding chronically ill patients under age 50). However, the question is whether the aim to script everybody in the design of the web site was supported by the technological choices that were made. This is an important question because it has implications for who is facilitated to be active and who is not, which is also of normative consequence – especially in the case of healthcare.

The technological choices seemed to be based on both macro and micro dynamics (Oudshoorn *et al.*, 2004). The wish to change the current healthcare system into a more patient-centered system, by stimulating personalized care and reducing fragmentation of care, was an influencing macro dynamic that fit within broader healthcare policy. It resulted in the idea to create a web site that, through use by active patients, would make the health network of the patient visible, leading to improved coordination and communication between physicians and between physicians and patients. However, the web site design was also influenced by micro dynamics, namely the I-methodology: designers own competences were used as a point of reference in the creation of the web site. The combination of these dynamics resulted in a scripted web site design that could be used optimally when patients had at least eight different types of skills and were facilitated to use these skills. However, not all users had these competences or had conditions, for instance leading to coordination problems, that influenced their ability to use the web site. As a consequence, users did not use certain aspects of the web site, used the web site in a different way than intended, or were even scripted-out (i.e. excluded from use) (see, e.g. Wyatt *et al.*, 2002), which makes it problematic to suggest that the web site was built for every Dutch citizen. It also makes clear that designers cannot only underestimate users' competences, leading to frustrated users who experience feelings of discrimination, as Ravneberg (2012) has illustrated, but that they can also overestimate users' competences, thereby influencing users' ability to use the web site. The level of design of assistive technologies must thus take different users with different conditions/(dis)abilities into account, as the specific characteristics of these groups can influence their degree, level or pace of "activity" (Czaja *et al.*, 2013), and often ask for specific web site design requirements (see, e.g. Fischer *et al.*, 2014). The importance of focussing on individuals and their interaction with computer systems, and thus on the functionality and usability of web sites, is also confirmed in human-computer interaction literature (Shackel, 2009).

The consequences of scripted designs not only have implications for the inclusion and exclusion of users, but also for the roles patients were expected to perform. Active patients were to become more integrally bound up in their own care, as well as in the care of others. They, for instance, had to help other patients by providing experiential knowledge, a process in computer sciences also known as "social scripting" (Lau, 2007). However, if patients do not know where to post their experiential knowledge (as they did not always knew the difference between functionalities), or when they do not use the web site in the "right" way (e.g. when they shared experiences through private e-mails instead of public messages), they could not contribute to the care of (many) others. Technological choices thus not only determine who is facilitated to be active and who is not, but they also influence the extent to which already active peers are able to perform health-related (self-care) activities. To meet the high expectations of ICT applications in healthcare, it is therefore important to keep monitoring whether technological choices still correspond with the goals that technologies have to establish.

The scripting literature of Akrich (1992, 1995) and Oudshoorn *et al.* (2003, 2004) used in this paper is helpful to illustrate that designers' technological choices and inscribing practices influence who is able or facilitated to become a (more) active patient and who is not, which is important to take into account in the active patient-ship debate. However, using this literature also illustrates another important aspect for this debate: By creating "scripts" patients are also able to deviate from these scripts (Akrich, 1992; Oudshoorn *et al.*, 2004), potentially leading to a "right" or "wrong" way to be active and doing the right kind of activity, but in the wrong place. Thus, the often-made distinction between "active" and "passive" in the active patient-ship debate, we argue, is insufficient for understanding daily practice, as there are more gradations to make. Because an understanding of activities that should be avoided or performed elsewhere could also clarify which types of activities could and/or should be performed (Eldh *et al.*, 2008), future research could focus on these kinds of activities to learn more about the active patient.

Designers adapted the web site according to “incorrect” use of it by active patients. As patients’ actions led to reshaping the technology, it illustrates that patients also function as web site co-designers. Although co-design activities to change and improve services usually take place by talking to users to bring their experiences to the fore to indicate improvement areas and solutions (Bate and Robert, 2007), co-design can thus also take place “indirectly” when technologies are adjusted on basis of observed user behavior. However, as our results indicate that it is not always possible to observe the “wrong” use of the web site and to reshape the web site accordingly, it remains crucial to include patients within the development of a technology, for example by interviewing them, to ensure better alignment between intended and actual uses (Eisma *et al.*, 2004).

Note

1. Since the choice for the communities and their characteristics was made prior to this study, it is beyond the scope of this paper.

References

- Aarts, J.W.M., Vennik, F., Nelen, W.L.D.M., Van der Eijk, M., Bloem, B.R., Faber, M.J. and Kremer, J.A.M. (2014), “Personal health communities: a phenomenological study of a new healthcare concept”, *Health Expectations*.
- Adams, S. and De Bont, A. (2007), “Information Rx: prescribing good consumerism and responsible citizenship”, *Health Care Analysis*, Vol. 15 No. 4, pp. 273-90.
- Akrich, M. (1992), “The de-scription of technical objects”, in Bijker, W. and Law, J. (Eds), *Shaping Technology/ Building Society. Studies in Sociotechnical Change*, The MIT Press, Cambridge, MA, pp. 205-4.
- Akrich, M. (1995), “User representations: practices, methods and sociology”, in Rip, A., Misa, T.J. and Schot, J. (Eds), *Managing Technology in Society: The Approach of Constructive Technology Assessment*, Pinter Publishers, London, pp. 167-84.
- Anderson, J.G., Rainey, M.R. and Eysenbach, G. (2003), “The impact of cyberhealthcare on the physician-patient relationship”, *Journal of Medical Systems*, Vol. 27 No. 1, pp. 67-84.
- Baker, T.B., Gustafson, D.H., Shaw, B., Hawkins, R., Pingree, S. and Roberts, L. (2010), “Relevance of CONSORT reporting criteria for research on eHealth interventions”, *Patient Education & Counseling*, Vol. 81 No. S1, pp. S77-86.
- Bate, P. and Robert, G. (2007), *Bringing User Experience to Healthcare Improvement. The Concepts, Methods and Practices of Experience-Based Design*, Radcliffe Publishing, Oxford.
- Bernard, H.R. (2006), *Research Methods in Anthropology. Qualitative and Quantitative approaches*, AltaMira Press, Lanham, MD.
- Boivin, A. (2012), *Patient and Public Involvement in Healthcare Improvement*, Radboud University Nijmegen, Nijmegen.
- Bowling, A. (2002), *Research Methods in Health. Investigating Health and Health Services*, Open University Press, Berkshire.
- Crawford, R. (2006), “Health as a meaningful social practice”, *Health*, Vol. 10 No. 4, pp. 401-20.
- Creswell, J.W. (2003), *Research Design: Qualitative, Quantitative, and Mixed Method Approaches*, Sage Publications, Thousand Oaks, CA.
- Czaja, S.J., Sharit, J., Lee, C.C., Nair, S.N., Hernández, M.A., Arana, N. and Fu, S.H. (2013), “Factors influencing use of an e-health website in a community sample of older adults”, *Journal of American Medical Informatics Association*, Vol. 20 No. 2, pp. 277-84.
- Eisma, R., Dickinson, J., Goodman, A., Syme, L., Tiwari, A. and Newell, F. (2004), “Early user involvement in the development of information technology-related products for older people”, *Universal Access in the Information Society*, Vol. 3 No. 2, pp. 131-40.
- Eldh, A.C., Ekman, I. and Ehnfors, M. (2008), “Considering patient non-participation in health care”, *Health Expectations*, Vol. 11 No. 3, pp. 263-71.

- European Commission (2014), "Households with Internet access at home", available at: <http://epp.eurostat.ec.europa.eu/tgm/table.do?tab=table&init=1&language=en&pcode=tin00088&plugin=0> (accessed September 11, 2014).
- Eysenbach, G. (2008), "Medicine 2.0: social networking, collaboration, participation, apomediation, and openness", *Journal of Medical Internet Research*, Vol. 10 No. 3, p. e22.
- Faber, M.J., Aarts, J.W.M., Van der Eijk, M., Vennik, F.D., Den Breejen, E., Putters, K., Kremer, J.A.M. and Bloem, B.R. (2012), *Het zorgnetwerk van de Patient. De eerste Ervaringen en Zichtbare Gevolgen voor de Gezondheidszorg (The Healthcare Network of the Patient. The First Experiences and Visible Impact on the Healthcare System)*, MijnZorgnet, Nijmegen.
- Fischer, S.H., David, D., Crotty, B.H., Dierks, M. and Safran, C. (2014), "Acceptance and use of health information technology by community-dwelling elders", *International Journal of Medical Informatics*, Vol. 83 No. 9, pp. 624-35.
- Hardey, M. (1999), "Doctor in the house: the Internet as a source of lay health knowledge and the challenge to expertise", *Sociology of Health & Illness*, Vol. 21 No. 6, pp. 820-35.
- Harris, R., Wyatt, S. and Wathen, N. (2010), *Reconfiguring Health Consumers: Health Work and the Imperative of Personal Responsibility*, Palgrave Macmillan, Houndsmills.
- Henkemans, B.O.A., Molema, J.J.W., Alpay, L.L., Schoone, M., Otten, W., Boog, P.J.M. and Rövekamp, A.J.M. (2010), "Innovaties voor zelfmanagement: ontwikkelen van diensten en technologie voor duurzame gezondheidszorg (Innovations for self-management: development of services and technology for sustainable healthcare)", *Tijdschrift voor Gezondheidswetenschappen*, Vol. 88 No. 3, pp. 112-16.
- Henwood, F., Wyatt, S., Hart, A. and Smith, J. (2003), "'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information", *Sociology of Health & Illness*, Vol. 25 No. 6, pp. 589-607.
- Lau, T. (2007), "Social scripting for the web", *Computer*, Vol. 40 No. 6, pp. 96-8.
- Lee, C., Gray, S.W. and Lewis, N. (2010), "Internet use leads cancer patients to be active health care consumers", *Patient Education and Counseling*, Vol. 81 No. S1, pp. S63-S69.
- Oudshoorn, N. and Pinch, T. (2003), "How users and non-users matter", in Oudshoorn, N. and Pinch, T. (Eds), *How Users Matter. The Co-Construction of Users and Technology*, The MIT Press, Cambridge, MA, pp. 1-25.
- Oudshoorn, N., Rommes, E. and Stienstra, M. (2004), "Configuring the user as everybody: gender and design cultures in information and communication technologies", *Science, Technology, & Human Values*, Vol. 29 No. 1, pp. 30-63.
- Ravneberg, B. (2012), "Usability and abandonment of assistive technology", *Journal of Assistive Technologies*, Vol. 6 No. 4, pp. 259-69.
- Rommes, E.W.M., Bos, M. and Geerdink, J.O. (2011), "Design and use of gender specific gender stereotypical toys", *International Journal of Gender, Science and Technology*, Vol. 3 No. 1, pp. 184-204.
- Schermer, M. (2009), "Telecare and self-management: opportunity to change the paradigm?", *Journal of Medical Ethics*, Vol. 35 No. 11, pp. 688-91.
- Shackel, B. (2009), "Human-computer interaction – whence and whither?", *Interacting with Computers*, Vol. 21 Nos 5/6, pp. 353-66.
- Shade, L.R. (2007), "Feminizing the mobile: gender scripting of mobiles in North America", *Journal of Media & Cultural Studies*, Vol. 21 No. 2, pp. 179-89.
- Steele, D.J., Blackwell, B., Gutmann, M.C. and Jackson, T.C. (1987), "The activated patient: dogma, dream, or desideratum?", *Patient Education and Counseling*, Vol. 10 No. 1, pp. 3-23.
- Van de Bovenkamp, H.M. (2010), *The Limits of Patient Power. Examining Active Citizenship in Dutch Health Care*, Erasmus University Rotterdam, Rotterdam.
- Van Loon, E., Oudshoorn, N. and Bal, R. (2014), "Studying design and use of healthcare technologies in interaction: the social learning perspective in a dutch quality improvement collaborative program", *Health*, Vol. 6 No. 15, pp. 1903-8.

Van Oost, E. (2003), "Materialized gender: how shavers configure the users' femininity and masculinity", in Oudshoorn, N. and Pinch, T. (Eds), *How Users Matter. The Co-Construction of Users and Technology*, The MIT Press, Cambridge, MA, pp. 193-208.

Vennik, F.D., Adams, S.A., Faber, M.J. and Putters, K. (2014), "Expert and experiential knowledge in the same place: patients' experiences with online communities connecting patients and health professionals", *Patient Education and Counseling*, Vol. 95 No. 2, pp. 265-70.

Vennik, F.D., Van de Bovenkamp, H.M., Putters, K., Grit, J. (forthcoming). "Co-production in healthcare: rhetoric and practice", *International Review of Administrative Sciences*, doi: 10.1177/0020852315570553.

Wyatt, S.M.E., Thomas, G.S. and Terranova, T. (2002), "They came, they surfed, went back to the beach: conceptualising use and non-use of the internet", in Woolgar, S. (Ed.), *Virtual Society? Technology, Cyberpole, Reality*, Oxford University Press, Oxford, pp. 23-40.

About the authors

Femke D. Vennik is a Doctoral Student at the Institute of Health Policy & Management of the Erasmus University, Rotterdam. With a background in health sciences, she is currently writing her doctoral thesis on the participation of patients in healthcare. Her research explores what it means for patients to become (more) active in healthcare, for example in terms of different roles and activities, and she studies the results and consequences of becoming more active. Femke D. Vennik is the corresponding author and can be contacted at: vennik@bmg.eur.nl

Samantha A. Adams is an Assistant Professor of patient-centered e-Health at the Tilburg Institute for Law, Technology and Society of Tilburg University. She is a Political Scientist with additional background in gender studies and science and technology studies. She is specialized in qualitative research methods and interested in developing methodological approaches for examining the ever-changing relationship between the internet and health(y) practices.

Kim Putters is a Professor of Health Policy and Governance at the Institute of Health Policy & Management of the Erasmus University Rotterdam. With a background in public administration, he developed specific interests in issues of (hybrid) healthcare governance and entrepreneurship. He is also the Director of the Netherlands Institute for Social Research in The Hague.

For instructions on how to order reprints of this article, please visit our website:

www.emeraldgroupublishing.com/licensing/reprints.htm

Or contact us for further details: permissions@emeraldinsight.com