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## Research and Applications

# Persistent inequitable design and implementation of patient portals for users at the margins

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### ABSTRACT

**Objective:** Diane Forsythe and other feminist scholars have long shown how system builders' tacit assumptions lead to the systematic erasure of certain users from the design process. In spite of this phenomena being known in the health informatics literature for decades, recent research shows how patient portals and electronic patients health records continue to reproduce health inequalities in Western societies. To better understand this discrepancy between scholarly awareness of such inequities and mainstream design, this study unravels the (conceptual) assumptions and practices of designers and others responsible for portal implementation in the Netherlands and how citizens living in vulnerable circumstances are included in this process.

**Materials and methods:** We conducted semistructured interviews (n = 24) and questionnaires (n = 14) with portal designers, health professionals, and policy advisors.

**Results:** In daily design practices, equity is seen as an "end-of-the-pipeline" concern. Respondents identify health care professionals rather than patients as their main users. If patients are included in the design, this generally entails patients in privileged positions. The needs of citizens living in vulnerable circumstances are not prioritized in design processes. Developers legitimize their focus with reference to the innovation-theoretical approach of the Diffusion of Innovations.

**Discussion and conclusion:** Although feminist scholars have developed important understandings of the exclusion of citizens living in vulnerable circumstances from portal design, other academic efforts have profoundly shaped daily practices of portal development. Diane Forsythe would likely have taken up this discrepancy as a challenge by finding ways to translate these insights into mainstream systems design.

**Key words:** Patient portals, minority group, inequitable design, feminism, patient engagement

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## INTRODUCTION: PATIENT INFORMATION, HEALTH INEQUALITIES, AND INCLUSION AND EXCLUSION IN DESIGN

Patient portals and electronic personal health records (ePHRs) are increasingly seen as tools that promise to support greater patient engagement while reducing costs and demands on the health system.<sup>1–4</sup> Patient portals and ePHRs are secure applications that can give access to (personal) health information and/or other functionalities such as self-management programs or online appointment scheduling.<sup>5,6</sup> An important difference is that the information in patient portals is owned by the health care providers and shared with the patient. In contrast, in ePHRs, the information is owned by the patients and to be shared by them with health care providers. Both applications have been linked to improvements in adherence to medication, management of chronic disease, disease awareness and self-care, and a decline in the number of outpatient visits of those with chronic diseases.<sup>1–4</sup> It is, therefore, not surprising that patient portals and ePHRs gained popularity in Western health systems.

Although researchers initially thought that these applications have the potential to reduce health inequalities,<sup>7,8</sup> recent insights point to the opposite. For example, a recent systematic review found more than 100 studies showing disparities relevant to *health inequality* in the use of patient portals (see Supplementary Appendix S1 for definitions of concepts).<sup>9</sup> *Populations living in vulnerable circumstances* including ethnic minorities, older people, persons with low socioeconomic status, low health literacy, chronic illness, or disability, disproportionately derive fewer benefits from these new technologies. Their introduction may, therefore, unintentionally reproduce the persistent problem of health inequality.<sup>9–11</sup>

The concern that interventions in health informatics disproportionately benefit more advantaged people is not new<sup>9,12</sup> and has been studied within health informatics as well as in the fields of computer-supported cooperative work (CSCW) and human computer interaction (HCI).<sup>11,13</sup> System-building processes reveal cultural values and disciplinary assumptions that are embedded in design<sup>14</sup> and the need for reflection on deliberate and unwitting design decisions.<sup>15</sup> As Diane Forsythe shows in her study of the development of medical technologies, “everyday medicine,” “medical knowledge,” “power relations between doctors and patients,” and/or “the relative importance of nurses” all influence the design of a computerized education system for patients.<sup>16</sup> A system that was designed to empower patients ended up reinforcing power structures between patients and doctors. Forsythe’s scholarship has thus been crucial in highlighting that users should be included in the design of innovative technologies.

The idea of the importance of including users has been extended to focus on design and involvement practices that explicitly address inequalities. In the fields of CSCW and HCI, further attention is paid to the problems in and around designing technologies, biases in computer systems that systematically and unfairly discriminate against certain groups, and problematic questions related to gender relations, class, and sexual orientation.<sup>13,15,17,18</sup> Most of these studies embrace theoretical insights from feminist technology studies<sup>19,20</sup> and/or intersectionality.<sup>21</sup> Feminist technology and intersectionality studies have offered important insights into power mechanisms that influence the inclusion or exclusion of certain groups in the design and use of technologies<sup>20–22</sup> and have been mainstreamed as *equitable design*.

The mantra of equitable design, however, does not always contribute to design change in daily practice, as equity has not been a

core concern in health informatics. This topic is more central to scholars in the fields of CSCW and HCI, but academic success in these fields has largely become defined in terms of the ability to report on “implications of design” or “theoretical insights” that come from ethnographic or observational field studies. This makes portal designers *de facto* gatekeepers for acting on these insights.<sup>23</sup> The uptake of the insights of showcases published in these fields seems rather limited, since the adoption of portals is still associated with higher socioeconomic status.<sup>4,10,24</sup> To unravel opportunities and constraints to mainstream equitable design, there is a need to study the assumptions and daily practices of portal designers and other professionals responsible for the implementation, since they influence design and implementation decisions that might (unintentionally) systematically and unfairly discriminate against certain individuals or groups.<sup>15</sup> Doing so can also help draw together the fields of CSCW and HCI on the one hand and health informatics on the other. This would raise the importance of equity questions within health informatics research while positioning questions of everyday design and implementation to the center of CSCW and HCI research agendas. Such a rapprochement could be 1 of the most promising contributions toward making design more equitable and one that this special issue on the legacy of Diane Forsythe could help facilitate.

This study focuses on the design practices of patient portals and ePHRs in the Netherlands. The Dutch government spurred the rapid uptake of patient portals and/or ePHRs in the Dutch hospitals by setting the goal that 80% of the chronically ill and at least 40% of the general Dutch population should have access to their own medical records before 2019.<sup>25</sup> The aim is to unravel the (conceptual) assumptions and practices of designers and other professionals responsible for the implementation of patient portals and ePHRs in the Netherlands in order to see how these assumptions and drivers may reproduce, strengthen, or otherwise reconfigure the dynamics of inclusion and exclusion of citizens living in vulnerable circumstances in design practices. We focused on designers as well as other professionals responsible for the implementation of these portals since patient portals are not developed in isolation and the (organizational) context in which these applications are implemented matters. Other professionals, such as health care professionals, organizational advisors, chief medical information officers (CMIOs) and quality/policy advisors, have a crucial say in selecting systems or developing rules and regulations for their implementation and could in this way potentially influence what vendors develop. Moreover, requests for changes tend to come from those professionals, making them a central link between designers and end users.

### Case: patient portals and ePHRs in The Netherlands

Studying the development of patient portals in the Netherlands is of international relevance since the characteristics of the Dutch health system combine national coverage with the market mechanisms of “regulated competition.”<sup>26</sup> As in other welfare states, the element of national health insurance ensures the need for providers to focus on citizens living in vulnerable circumstances. But the market-regulation aspect, which served as 1 of the models that influenced changes in the regulation of US health care,<sup>27</sup> makes the Dutch development of patient portals relevant for market-oriented health systems too. Providers operate in an environment in which they compete for insurance contracts and patients. These characteristics make the findings from studying Dutch portal development relevant for a wide range of health systems.

**Table 1.** Overview of participants

	Function	Focus on implementation versus development	Affiliated organization	Organization size <sup>b</sup>	Main application of discussion
1	Medical doctor <sup>a</sup>	Implementation	Hospital	General hospital	Patient portal
2	CMIO	Implementation	Hospital	General hospital	Patient portal
3	RN	Implementation	Hospital	General hospital	Patient portal
4	a) Nurse b) Nurse	Implementation	Hospital	Academic hospital	ePHR
5	a) IT consultant  b) RN eHealth	Development and implementation	Hospital	Academic hospital	Patient portal
6	IT consultant	Implementation	Hospital	General hospital	Patient portal
7	IT consultant	Implementation	Hospital	General hospital	Patient portal
8	eHealth programme manager	Implementation	Hospital	General hospital	Patient portal
9	Policy adviser	Implementation	Hospital association	n/a	Patient portal
10	IT consultant	Development	Software company	Large company	Patient portal
11	Software developer	Development	Software company	Large company	Patient portal
12	Product manager	Development	Software company	Start-up	Patient portal
13	Research and Development manager	Development	Software company	Large company	Patient portal
14	CEO	Development	Software company	Medium company	Patient portal
15	Software developer	Development	Software company	Medium company	Patient portal
16	CEO	Development	Software company	Start-up	ePHR
17	CEO	Development	Software company	Start-up	ePHR
18	IT consultant	Development	Software company	Start-up	ePHR
19	Program management	Development	Software company	Start-up	ePHR
20	Software developer	Development	Software company	Small company	eHealth
21	Managing director	Development	Software company	Small company	eHealth
22	Policy adviser eHealth	Implementation	Knowledge Institute	n/a	Patient portal and ePHR
23	Policy adviser eHealth	Implementation	Knowledge Institute	n/a	Patient portal and ePHR
24	Policy adviser eHealth	Implementation	Knowledge Institute	n/a	Patient portal and ePHR

*Abbreviations:* CEO, chief executive officer; CMIO, chief medical information officer; PHR, patient health record; PP, patient portal, RN, research nurse.

<sup>a</sup>With interest in diversity.

<sup>b</sup>Small company < 40 employees; medium company < 100 employees; large company > 100 employees.

Moreover, the Dutch health system is served by a large number of patient portal providers. Although the hospital market is dominated by a small number of major players, as it is in the US, general practitioners and care providers for people with mental and physical disabilities or elderly people implement ePHRs from a wide range of smaller providers. This means that the findings from our study are less influenced by the development practices of just one or two dominant players.

Despite ensuring universal coverage, Dutch citizens with a low socioeconomic position live 7 years less, and enjoy 19 years less in good health than those with a high socioeconomic position.<sup>28</sup> The former therefore also need to make more frequent use of the health system, but are also likely to find it more difficult to use information and communication technologies. These citizens tend to have little or no access to digital devices, poor digital skills,<sup>29,30</sup> and greater difficulties in obtaining high-quality support from their surroundings.<sup>31–33</sup> It is, therefore, not surprising that better-educated patients make more use of patient portals<sup>4,34</sup> and so are able to navigate the current health system.

## MATERIALS AND METHODS

This study is nested in a larger study on digital inequality in Amsterdam. Analyses of the needs of citizens with a low socioeconomic position, which are published elsewhere,<sup>31,35</sup> highlight that it would be more effective to adapt web-based information to meet their needs

than to educate these citizens to use complex applications or websites that have not been designed for them. To unravel whether this is feasible in practice, this study focuses on the perspectives of designers, health care professionals, and policy makers. To study their conceptual assumptions and main practicalities, we opted for a qualitative research design. We gathered data using semistructured interviews and open-ended questionnaires (see [Supplementary Appendices S2 and S3](#)).

Using purposive sampling, we ensured that the data were gathered from representatives who have experience with the topic discussed. It proved challenging to find participants for the interviews that were solely dedicated to patient portals or ePHRs. Often multiple functions and positions are associated with developing, implementing, or maintaining these portals. These functions vary according to the hierarchical position, responsibility, and background, such as information management and the doctors or nurses charged with IT tasks. In total, we conducted 24 semistructured interviews with 26 respondents working in a hospital (n = 10), software company (n = 12), knowledge institute (n = 3), or hospital association (n = 1) ([Table 1](#)). Ten of the interviewees were focused on the implementation of patient portals and/or ePHRs, while the other interviewees were focused on their development ([Table 1](#)). Based on the total sample of 26 respondents data saturation was reached since we gained comprehensive insights into the assumptions and practices of designers, health care professionals, and policy advisers, including various examples of the link between their assumptions and practices. After conducting the first set of 13 interviews and having re-

ceived the questionnaire data, we analyzed these for initial coding. We then continued with conducting the remaining 11 interviews. These initially still raised additional topics or refining of the code-scheme, while during the last interviews no new topics emerged in relation to the research question.

A semistructured interview guide included questions regarding 1) needs to make patient portals and/or ePHRs accessible for everyone; 2) mechanisms that support or prohibit the inclusion of citizens living in vulnerable circumstances; and 3) awareness of people with low digital skills. Participants were first asked about patient groups who might be excluded from patient portals or ePHRs after which the interviewer introduced the focus on citizens who struggle with portals because of their limited digital skills. The interviews were conducted between March 2017 and November 2018 by JW (n = 13) and students (n = 11), all supervised by NG and CD. The interviews lasted between 30 and 90 minutes, and were conducted in Dutch (n = 22) or English (n = 2). With participants' consent, all interviews were audio recorded and transcribed. A member check was performed by sending a summary.

In addition, a questionnaire was sent to CMIOs to complement the interview data. Fourteen of the 44 CMIOs returned the online questionnaire. Thirteen worked in general hospitals, and 1 at a university hospital. The questionnaire consisted of 4 closed and 5 open-ended questions. The small number of respondents to the questionnaire allowed us to meaningfully analyze the data only qualitatively. The open-ended questions provided room for elaboration of the closed questions and were focused on the themes 1) awareness; 2) responsibility; 3) eHealth policy; and 4) needs.

## Analysis

Full transcripts and open-ended answers were analyzed through thematic analysis. The data were coded with the help of the coding software ATLAS.ti and followed the 6 steps of thematic analysis as identified by Braun and Clarke: 1) familiarization; 2) initial coding; 3) searching for themes; 4) critically reviewing themes; 5) defining themes; and 6) producing the article. An inductive approach was chosen to ensure that themes were effectively linked to the data.<sup>36</sup> One researcher (NG) coded the data which were reviewed and refined by 2 others (TZJ, JW). All authors were involved in the last 3 steps of thematic analysis and agreed upon the final coding scheme, themes, and findings.

## RESULTS

Four themes were developed: 1) Who is considered an end user? 2) Homogeneity of patient voice; 3) Awareness of the group that is often forgotten; and 4) Who is considered responsible? We refer to both patient portals and ePHRs as “portals” and make it explicit only when a result refers exclusively to one or the other. Questionnaire and interview data complemented each other and are portrayed in an integrated manner. No major differences were found between designers of small, nationally operating companies or large international ones nor between health care professionals working in general or university hospitals.

### Who is considered an end user?

Software companies define health care providers and, to lesser extent, health insurance companies as their “users.” To illustrate this, a CEO (P14) mentions: “I am a software developer and my client is the doctor, you know?” In the Netherlands, patient portals and

ePHRs are provided to the patient by health care institutions. Therefore, also, health professionals often refer to portals as “their” applications. Just 1 software developer of an ePHR (P20) explains that the patient is his first priority, as she or he should be able to use the application; he sees it as his challenge to make sure it can also be used by doctors. In general, however, the focus is on the wishes and needs of health professionals and ensuring that the application works in the current health system.

*It is indeed the case that what we do as information and communication technology (ICT) department is driven by the requesting party, and this requesting party are the screaming health care professionals. You don't hear the patient, because they don't shout, they are sick, and are taken care of by the health care professionals. (P6, Hospital)*

For example, 1 of the interviewees highlights that it is technologically possible to have an application in simplified language, but that also requires adaptation to health professionals' current work practices. For health professionals, the language should not be too simple, since this will result in medically imprecise information. Moreover, doctors are accustomed to writing in technical jargon and do not have the time to translate these terms into simplified language. To illustrate this, an IT consultant (P6) mentions: “That is not what you want. You don't want to intervene [with] a health care professional in the way he or she expresses him or herself.” This example shows that designers are highly constrained by dominant end users, so the term “user involvement” conceals the inherent dynamics of inclusion and exclusion.

### Homogeneity of patient voice

While the development and implementation of portals seem to be driven by IT developers, with input from health professionals, the patient's voice is not entirely excluded from this process. Interviewees highlight that the portals need to be easy to use and interesting enough to boost the number of patient users. A minority of the developers use their own (patient) experience or get feedback from their own employees because they are patients themselves. To illustrate this point, an IT consultant (P10) comments: “And that is why we use the experiences and insights from our 10 000 employees who almost all use a portal.”

Most developers go a step further and mention that feedback from patients is integrated in the design and implementation phase. They mention that patients' or citizens' input is highly valued and is beginning to become more central in the development of portals. For example, a software developer (P11) mentions: “So, usability becomes more and more important. More user experience design to make the portal easier, more attractive, and interesting to use.” The interviewees mention several tools to include the patient's voice during design and following implementation, including client boards (n = 5), patient panels (n = 1) or patient associations (n = 2), usability tests (n = 3), patient feedback via health professionals (n = 3), complaints through help desks (n = 1), patient survey (n = 1), face-to-face feedback sessions on design (n = 2), e-mail from assertive patients (n = 1) or (informal) interviews (n = 1). Patients are included most frequently in a one-off event and, on occasion, they are approached several times. None of the interviewees, however, mentions a long-term partnership in design or implementation of portals.

The voice of the patients who are included, however, seldom corresponds to an average patient population, let alone represents those who are living in vulnerable circumstances. Most tools focus on

feedback from patients who already use the portals. Moreover, interviewees highlight that client boards, patient panels, and/or associations seldom represent patients with low literacy or poor digital skills and tend to represent those of higher socioeconomic position and education. For example, an IT consultant (P7) highlights: “*But the patient who we reach out to, the one who most likely joins a panel [...] we reach out to them by mail. So, it is very likely that all these patients have some digital skills. So, we won't get a representative group.*” Interviewees underlined that it is hard to find a representative group of patients, including among those in more vulnerable circumstances.

Some assume that patients living in vulnerable circumstance do not want to be involved or claim that it is too difficult to involve them. For example, a policy adviser (P24) mentions: “*Often they say they are hard to reach, and that is the case. In an early stage of the design trajectory, it is often a major challenge if they have no idea what a patient portal is. What can you talk about?*” Some interviewees shared good examples of the inclusion of a diverse patient group, such as a patient panel established in a community center rather than in the hospital. However, they all stress that it is costly and takes more effort to include citizens in vulnerable circumstances.

*You need to invest in this and set the step outside the hospital. [...] Go for example to the mosque at the end of Friday prayers, it will be busy. Sit there and ask people whether they would like to answer some questions. And I would invite a Moroccan student, so I have someone who can help with the language.* (P1, Hospital)

While in practice a more or less homogeneous group of patients is included, interviewees reflect that it seems impossible to have 1 generic portal for everyone. Various respondents highlight the need for more personalized portals, since no system will fit everyone's needs and wishes. Two interviewees underscore the need for personalization to accommodate certain groups, such as nonliterate people or elderly people with poor vision. For the majority, however, personalization is based on diagnostics; personalized portals for a certain disease or a group of patients with the same disease characteristics.

*Another aspect is that you can have modules for a specific disease, so an asthma module, a heart failure module, a kidney failure module. And maybe a module for newly diagnosed people with asthma and for people who already [have had] asthma for 30 years.* (P20, Software company)

The focus on diagnostics influences the way portals are personalized. Groups who are not in a historical medical category (eg, citizens who live in poverty or with a different cultural background) are not often mentioned.

### Awareness of the group that is often forgotten

The majority of the respondents do not seem familiar with, and sometimes not even aware of, the group of patients who often have greater difficulties in using new technologies, such as patients with a low literacy level or socioeconomic position. One of the respondents made this explicit:

*When I refer to myself for a moment, I also grew up in a bubble. I went to a primary school and high school for highly educated families, and then I went to the university. So, you don't actually see those groups [citizens who live in poverty or with low education levels].* (P24, Knowledge institute)

Another software developer (P20) mentions: “*The idea that apps are for young people, and people aged over 65 won't understand these, is a really outdated idea.*” Although this age-based divide is indeed shrinking, there are also other citizens who have difficulties in using ICTs.

When the participants were asked about patient groups not using a portal, and who might be excluded from doing so, they mentioned patients with dementia or visual impairments or those who do not want to engage. Only a few refer to patients with low literacy, a lower socioeconomic position, or educational level as factors determining nonuse. When the interviewer introduced the fact that citizens with lower socioeconomic position have difficulties in using the portals, in the follow-up answers almost all interviewees still refer only to citizens with limited literacy and not to patients having difficulties in using portals due to poverty or low education levels.

In addition, the minority who are aware of this group often downplay the issue of digitally excluded citizens by stressing that it is a really small group, and that the problem has limited or no negative effects.

*I know there is a group, people who are digitally excluded. [...] in the sense they don't want to or they can't. Or just don't have the correct device. I worry about this group. So, I talk about it sometimes with the patient counsel. But this group is not so large. I am wondering what you think, but I think it is not that big of a deal.* (P2, Hospital)

Only one of the designers highlights that this lack of awareness of health inequality is one of the things that should change in order to make our health system more inclusive.

*People will get excluded. They will not have access to tools to manage their care. This is a national problem. And I think these people already have a hard time, are risk groups in healthcare, won't have tools to improve it, and will only get behind even more. It starts by acknowledging that problem.* (P11, Software company)

So, either not acknowledged as a problem, or recognized as a problem, but who owns it? Do respondents see any role for themselves?

### Who is considered responsible?

Most of the interviewees highlight that not they, but another stakeholder in the health system, is responsible for ensuring that the technologies can be used by everyone. Only a minority refer to shared responsibility. Moreover, there is no agreement on which stakeholder is responsible. For example, in the questionnaire, the CMIOs refer to a wide range of stakeholders including medical informatics departments, patient advisory boards, doctors, nurses, medical information professionals (including the CMIO), and the government. Most interviewees working in hospitals highlight that the government, insurance companies, or, in some cases, the designers should take responsibility. In contrast, the designers most often point to health professionals and insurance companies.

Reasons for why they do not feel responsible are diverse between and among the different interviewees. Some mention that a technology is not a solution to unequal access to health care or social inequalities and suggest that the solution to the more fundamental (social) problems is beyond the development and implementation of a technology. A few developers add that a certain group of people will never be reached by certain essential technologies.

*Everyone who comes here [in the hospital] and would like to know something about the portal. [...] Often, they ask something about health inequalities. And then I say: I get it, a fair question. A really good one, but we are not going to solve it [health care inequalities]. For people who don't speak Dutch, we are not going to solve it. (P5, Hospital)*

Some emphasize that families or friends should step in and make sure that citizens in more vulnerable circumstances could also use portals. To illustrate this, a CEO (P14) highlights: “*But what we see quite often, the patient has also people in his or her surrounding, you know.*”

In contrast, some argue that it is technologically possible to find solutions to fit the needs of all citizens. Many developers mention, for instance, that it is technically possible to translate the portal; but portals in the languages of minority groups in the Netherlands are not yet available. Some state that they will only come up with new technological solutions if the unintended effects become visible. To illustrate this, a managing director (P21) explains: “*Health care professionals don't face any problems. [...] You can still send a letter or you can just call the patient.*” So, unequal access to portals is not a problem to be tackled as long as alternatives are available.

Moreover, there is general tendency for respondents to first make sure there is a solid and sustainable technology and, therefore, focus on those who are interested. Implicitly referring to insights of Rogers' diffusion of innovations theory (DOI) they prefer to focus on the early adopters and assert that the laggards, or “the ones who are not interested” yet, will come on board later:

*We did not choose to identify the group that feels digitally excluded and to develop and implement the portal with them. We chose to go with early adopters, to put forward a solid portal in a project-based way. (P5a, Hospital)*

Whereas this respondent literally uses a central concept from DOI (“early adopters”), others draw on the same conceptual notions without necessarily using the exact terms to explain design choices which are based on the assumption that innovations should first reach the critical mass to only then focus on the remaining adopter groups.

*I am very clear about that. If you can reach 60% of the COPD patients, it's way better than 0%. If you reach those 60%, next you can still focus on the 40% who have more difficulties. (P18, Software company)*

Only one interviewee reasoned from a feminist perspective and highlights the need to focus on the groups who have greatest difficulties.

*While I think it is better that you design something for the group who has most struggles to use these technologies. If they can use it, then other groups can use it as well. If you do it the other way around you will exclude a group. (P22, Knowledge institute)*

Last, interviewees highlight economic or efficiency reasons. Commercial developers would like to have as many users as possible since that makes their product profitable. For example, a policy adviser (P23) mentions: “*It's really harsh to say, maybe, but sometimes if you develop a product and you are quite sure that at least a million people are going to use it then you focus all your efforts on the people that are willing to pay for it.*” In addition, hospitals often refer to the VIPP program (for more information go to: <https://www.vipp-programma.nl/>), a Dutch government program which will subsidize the implementation of a patient portal only if it reaches 40%

of their patient population. Efficiency reasons are also highlighted, since focusing on the largest group possible will make the product more efficient for health care in general.

## DISCUSSION

This article studied the conceptual assumptions and practices of professionals responsible for the design and implementation of health-related portals and describes how these assumptions and practices influence the way voices of citizens living in vulnerable circumstances are reflected or denied. Designers are mostly focused on what is needed to make their product “successful,” which means a financially sustainable product that works for a large group of patients. Making a financially sustainable portal in a market-oriented health system requires collaboration with major actors, such as hospitals and insurance companies. Otte-Trojel et al use the metaphor that “building a shop in an empty street doesn't make sense”; the new technology needs to be embraced by multiple actors in the health care infrastructure.<sup>37</sup> It is not surprising, therefore, that hospitals and insurance companies are seen as clients, and that the needs and wishes of the “real” end users, patients, are not central in the development of a portal. The concern here is to ensure that bridging the gap between designers, health care professionals, and policy makers on the one hand and unspecified “users” on the other, does not contribute to widening the gap between different user groups.

Designers (implicitly) refer to some theoretical insights from the DOI theory,<sup>38</sup> which is perhaps unsurprising, since this theory has been described as the “mental furniture of our everyday life.”<sup>39</sup> Rogers highlights that an innovation is adopted after going through several stages led by different types of consumers—innovators, early adopters, early majority, late majority, and laggards. Reflections on DOI have highlighted its link to determinism and imperialism—the standard model of Western colonialism: innovators are seen as superior to the adopters who can merely reject or accept technology.<sup>39,40</sup> In line with Rogers, interviewees felt that the nonusers, or laggards, should not be included in the design process, since including them will not lead to a broad adoption of a technology. They believed they are justified in basing their process on the assumption that they should focus on the early adopters and that the laggards will follow automatically—or not. These underlying assumptions are in sharp contrast with feminist technology<sup>19,20</sup> and intersectionality<sup>21</sup> studies that emphasize the need to address power dynamics that influence the inclusion or exclusion of certain groups in the design of technologies. In his work, Rogers<sup>38</sup> in fact did warn that innovations can lead to greater inequality and that the role of any change agency should make special efforts to possibly narrow, but at least not widen, this gap. So, the DOI is somewhat more nuanced than the designers suggest in the interviews. However, the version of DOI that has travelled to design settings like the one studied here seems to have lost that nuance along the way.

We also observed that the transition from a paper-based health care system toward a more electronic one is considered to be a complicated endeavor, and consequently the needs of citizens living in vulnerable circumstances will be taken into account “later,” as will policies concerning health inequality. In the literature on health informatics, patient portal studies also focus on support for patients in navigating a provider-centered technology rather than equitable design early in the process.<sup>41</sup> Health equality is an end-of-pipeline practice—one that designers and medical professionals prefer not to talk about. In the interviews, most seemed comfortable only with referring to citizens who are excluded because of physical impair-

ments, age, or literacy levels. Research into the digital divide, however, highlights many more minority groups who have difficulties with digital technologies, such as citizens living in poverty, with a limited educational background, or who are non-Western immigrants.<sup>31,42</sup> In the development and implementation of patient portals, more attention needs to be paid to people with limited digital skills and the intersection between sociodemographic characteristics, such as ethnicity, class, age, gender, or disability, that influence the way technologies are used or not.<sup>11,21,31,43</sup>

Finally, and importantly, we found that neither designers nor hospitals felt they were themselves responsible for these groups. In addition, Dutch government policies do not explicitly highlight the inclusion of citizens living in vulnerable circumstances in the design and implementation of patient portals. Patients are included in the design to make the products more acceptable for the “average” patient. It is very seldom understood that without the deliberate inclusion of minority groups, there is implicit exclusion.<sup>22</sup> In her work, Lynch<sup>44</sup> argues that within a health system there is a historical tendency to prioritize medical problems and that there is less of a need to counteract health inequalities which are primarily a consequence of social inequalities.

## CONCLUDING REMARKS: MAINSTREAMING EQUITABLE DESIGN

In the academic fields of CSCW and HCI, it is well known that design of technologies is deeply intertwined with inequality and exclusion. This widespread understanding can be seen as the legacy of the generation of feminist scholars.<sup>16,20–22</sup> This study highlights that despite the mainstreaming of such insights in these academic fields, in the day-to-day practice of portal design, there is only a very limited or no sense of urgency to achieve equitable design. The next challenge in safeguarding the legacy of Diane Forsythe and colleagues, who have long shown how system builders’ tacit assumptions lead to systematic erasure of certain users, is therefore to ensure that such insights make a greater contribution to design and implementation practices to address such inequalities. The insights made by such scholars within their own academic fields simultaneously create the risk that they remain confined to conference proceedings and academic careers, rather than help address the problems they helped to highlight.

The scholarly success of HCI and CSCW, which originally brought together the separate disciplines of social sciences and computer sciences, has professionalized these scholars into new scientific fields, populated by scholars who are interdisciplinary by training.<sup>45</sup> This reintroduced the challenge of how to transcend the borders between these thriving scientific fields and those fields where patient portals and ePHRs designers draw upon and are educated in. By this we refer to the borders with fields like health informatics, and by extension also to the everyday practice of commercial eHealth developers. The academic success of an important generation of scholars in the fields of CSCW and HCI who focused on inequitable design seems to have strengthened the disciplinary compartmentalization (ie, distance to health informatics as a field) they had set out to challenge. In parallel with the academic success of these fields, in research on health informatics there is still more focus on individual patient barriers than on incorporating equitable approaches early in the portal life cycle.<sup>41</sup>

Simultaneously, we were struck by the number of relatively explicit references to the instrumentalist version of the DOI approach.

This theory was invariably used to justify postponing the inclusion of users living in vulnerable circumstance by the linear move of “scheduling [it] into the future”<sup>46</sup> of diffusion. This discrepancy between the academic success of important theoretical insights about inequality in ICT design and the success of theoretical notions that prioritize innovators over adopters among system builders is an irony that scholars like Diane Forsythe would have been likely to take up as a next challenge.

In order to mainstream the equitable design of patient portals in design and implementation practice, CSCW and HCI scholars need to continue to take their work “outside the [conference] hotel”<sup>47</sup> to create ripples of change in the field of health informatics and in daily design practices. Cooperating closely with main stakeholders like (mono-disciplinary) trained patient portal developers or policy makers seems essential to not only better understand bureaucratic or commercial barriers to equitable design but also to find ways to enlist such actors into equitable design. To change a design culture in which the involvement of citizens living in vulnerable circumstances is seen as costly and difficult, a rapprochement between the fields of CSCW and HCI on the one hand and health informatics research and design practices on the other seems more important than ever.

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## AUTHOR CONTRIBUTIONS

NG, WB, CD, JW, and JB made substantial contributions to the conception and design of the work. JW and NG were responsible for the data collection and supervised by CD and WB. NG and TZJ were involved in the interpretation of data. NG and TZJ drafted the manuscript, and CD and JB critically reviewed and edited the manuscript. All authors gave approval for the final version to be published.

## SUPPLEMENTARY MATERIAL

Supplementary material is available at the *Journal of the American Medical Informatics Association* online.

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## CONFLICT OF INTEREST STATEMENT

None declared.

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