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Petersen, Lone Stub; Bertelsen, Pernille Scholdan

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Equality Challenges in the Use of eHealth: Selected Results from a Danish Citizens Survey

Lone Stub Petersen, Pernille Bertelsen

Department of Development and Planning, Aalborg University, Aalborg, Denmark

Abstract

The increased focus on and use of citizen/patient generated health data has spurred a wide range of personal health technology projects within digital intervention in health, e.g. telehealth. These developments are focused on objectives of improving health, but also claiming to provide health services at a lower cost. However, the question is: do the ways healthcare technologies are designed and developed support and improve healthcare services for those who need it the most?

Survey data from our study point toward health informatics challenges in reaching the people who are considered in 'health risk' group, who, in this study, are interpreted as people with low level of education. The study shows that this group is less likely to use and communicate through health information technologies (HIT) and is generally more sceptical towards the benefits of HIT.

We conclude that there is a need to pay specific attention to the patient groups that are socio-economically and health wise weakest during HIT design and development. It would also provide equality and equity in digital health intervention and access to healthcare for them in the future.

Keywords:

Surveys and Questionnaires; Educational Status; Health Services

Introduction

Today we see an increased focus on the use of patient-generated health data (PGHD) both developed for consumers interested in improving their own health, and for use in the healthcare sector [1], where many healthcare professionals and health care managers see an enormous potential in HIT to improve service and reduce costs. The potential usefulness is seen as enormous but we know little about a) who uses the technologies and b) how these data can benefit/support health care services [2].

Table 1 – Two categories of data generated by patients

Citizens - person/patient-generated health data (C-PGHD)	Healthcare professional - person/patient-generated health data (HP-PGHD)
Generated by citizens/patients for citizens/patients	Generated by citizens/patients for healthcare professionals
Controlled and owned by the citizens/patient	Controlled and owned by the healthcare professional

The two perspectives on PGHD presented in Table 1 have data generated by patients as common ground but differ when it comes to the objective or purpose of why patient data is collected and also when it comes to purpose of its use. The commonly used terms, when it comes to framing the intersection between citizen or consumer generated data and the use or non-use of these data by health care professionals are patient or person generated data (PGD) and/or patient generated health data (PGHD). Person or patient generated health data (PGHD) can be defined as health-related data created, recorded, or gathered by patients (or by their family members or other care givers) for own use or to be shared with their health care providers [3]. We will go into depth first with the citizen/patient perspective and then the health care professional perspective in the following section.

Citizens perspective in HIT and patient generated health data. (C-PGHD)

Citizens and patients are beginning to use a range of health information technologies (HIT) to track and generate personal health data outside the clinic. Today, numerous types of HIT and more contemporary consumer health technology are migrating from being expensive "first movers" toys to becoming inexpensive and generally available to the more average consumers. These technologies provide patients the ability to track their own health data [1]. Some of the best known platforms supporting and encouraging people with smartphones to track their own health are Apple's HealthKit [4] and Google's Google Fit [5]. The potential of using PGHD data are seen as enormous but it still remains to be seen how best to integrate these data into contemporary clinical work, and to make sure those in most need also are those being encouraged to collect own health data and thus benefit from the use of the health data.

Market developments predict that consumer technology for health management will continue to increase – it has been estimated that wearable health technology will become the eighth largest revenue driver within consumer and mobile devices in 2018 [6]. This increase shows strong indications on citizens' interest in everyday health management. Simultaneously, this has sparked increased interest from health professionals to explore how to include patient generated health data as part of clinical practice and electronic health records [3].

This development, often framed as Quantified self or life logging, enables patients to capture, measure, track, and analyse data from and within their daily life (e.g. physical activity, food consumption, mood). Availability of relatively inexpensive wearable technologies and availability of digital storage of personal data offline and on-line has made personal HIT a research topic [7]. Now citizens are able to gather and store

large volumes of personal data in a very cheap manner, e.g. by using their smartphones.

This availability of data put pressure on the health professionals to include these technologies in their treatment. How the challenge materializes in the clinical setting depends, among other things, strongly on the type of national health care system governance, for example, the degree of public, private, and health insurance financed health interventions. The healthcare sector will need to meet the challenge by developing and implementing digital health interventions (DHI) [8] and by enrolling patients.

Healthcare Professionals, eHealth and patient generated health data (HP-PGHD).

Citizens and patients are still in the upstart of exploiting HIT to either support their own management of health and diseases at home or to supplement the service provided by their health care provider [8]. DHI aimed at the public or citizens in general have a wide span from telehealth and telecare systems to mobile health applications and devices [9, 10]. As a result, new HIT tools are becoming available for clinical practises to potentially be integrated in their health interventions, and are also available at the market for citizens to buy and use in their private sphere. Mobile technologies for self-monitoring of wide-ranging variables such as blood pressure, physical activity, blood glucose, daily weights, sleep etc. are available and question the traditional patient-physician relationship [11].

Challenges of PGHD when used in the clinical context of healthcare professionals include the reliability and accuracy of the data collected, forgetfulness of patients, e-health literacy, attitudes towards technology, and patients' self-bias [12]. However, the innovative technologies and the change of culture related to Quantified Self have opened up the potential for patients to collect more accurate and reliable health data [3].

In addition to DHI, another form of PGHD used in clinical settings are Patient reported outcomes (PRO) and Patient Reported Outcome measures (PROM). PRO is information on patients' health and quality of life, reported directly from the patient to be used by health provider organizations as a feedback and quality assurance measurement system on local as well as national levels. PRO is information about a patient's health, including physical and mental health, symptoms, health related quality of life, and functional level [12, 13, 14]. Patient reported data could inform different aspects of patient experience, from their encounter with the healthcare sector, for example, the structure, processes and results [16]. Patient Reported Outcome measures (PROM) may be seen as a subcategory of PRO where the systematic collection of data on patient experiences are measured at, for example a national level, as is seen with NHS in England [13], and the Danish Cancer Association [14].

PRO and PGHD are both concepts that feed into a debate on who uses and how to make use of and learn from, the data patients generate in different health care provider settings and while developing DHI. PRO and PROM, as well as tele health information are structured by and feed into clinical practice in a format that clinicians have control over. This is not the case with C-PGHD. These data are not formally structured but have the same quality assurance issues as the HP-PGHD. This makes it difficult for clinicians to agree on their usefulness in daily clinical practice and therefore to integrate these data into the existing healthcare services.

Health inequality – The Socio-technical challenge of HIT

In this context of C- and HP-PGHD, we like to argue for the importance of a social investigation of who the users of the HIT are, and when doing so keep an eye on whether the in-

creased use of HIT in healthcare is decreasing or increasing health inequality in society. The World Health Organisation (WHO) defines health inequalities as “avoidable inequalities in health between groups of people within countries and between countries” and describes health inequality as significantly influenced by social determinants [15]. It is paradoxical that despite a long tradition as a welfare country, and a relatively low income gap between rich and poor, Denmark is a country that within the last 25 years has doubled health inequality (measured on mortality) [16] This inequality does not only need to be handled through healthcare governance, but needs to be addressed when developing HIT.

Showell and Turner from an Australian context [17] argue that most HIT claiming to be of use for patients, are designed and developed, and therefore being used, by “people like us” (PLU). ‘People like us’; that is, “people who believe to understand healthcare and health issues, take care of their own health, are literate, well to do, tech-savvy, and hold a tertiary qualification” [17]. On the other hand, those citizens who really are in strong need of better health, care, and support are the disempowered, disengaged and disconnected, the DDD’s. If this is indeed the case and most health promoting IT used in DHI reinforces health inequality, there should be a motivation for understanding and contributing to change in development of HIT.

In this paper we report on selected findings from the 2015 survey based on data from eight questions (20A, 20I, 20B, 22A, 21A, 23, 24,) [18] that explore the citizens' experiences with accessing and using a) the national health portal Sundhed.dk, b) consumer apps and internet and c) mobile health apps and services. Educational background data have been analysed to investigate if a difference in use of IT correlate with respondent's educational background. Education is free for all citizens in Denmark, and has been so for more than a century. Therefore, all citizens have at least a primary school education. Further, educational level, socio-economic status, and health are strongly related in a Danish context. This is the reason education is used as an indicator of socio-economic and health status in this analysis of inequality. We acknowledge that this might not be the case in all countries, however, we are confident that similar challenges of the reproduction of inequality in eHealth can be found in other countries.

Methods

The survey reported from in this paper is the second in a bi-annual series of National surveys on Danish citizens' expectations and perspectives on eHealth. The first was done in 2013, inspired by Canadian and Australian studies of consumer experience with eHealth [18,19]. The second survey in 2015 was further inspired by questions posed in national surveys from Norway and Finland. The survey is supported by Danish eHealth Observatory and The Danish Center for Health Informatics who have monitored eHealth implementation in Denmark for many years such as the national implementation of the Electronic Health Record (EHR) and the national monitoring of clinicians' use of health informatics in their daily practices. A Danish market research agency (Megafon) was commissioned to carry out the surveys with a population sample of n=1,059 in 2015 and n=1,058 in 2013. The questionnaires were tested twice. The surveys are combination of using both email and telephone. The selected respondents are part of a citizens' panel reflecting the Danish adult population with respect to age, education, and geographic distribution.

Results

People with only primary school education are less likely to use the Danish national health portal than those with higher education (Sundhed.dk in Figure 1). Only 21% of people with only primary school education have used the portal while 60% of people with a high education have used it.

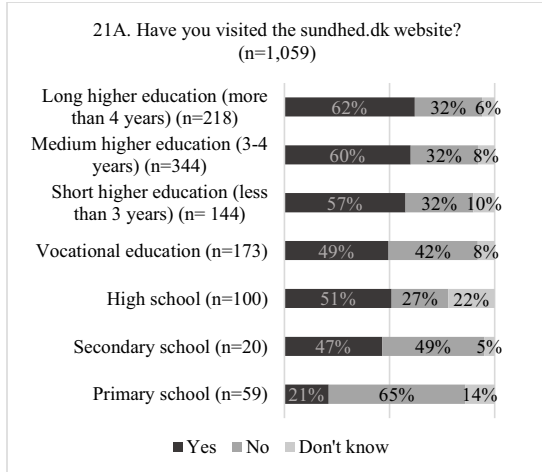


Figure 1 - Cross Table: Educational Level and Expected Impact of Health IT

Citizens with only primary school education have less experience with using applications developed for health purposes (8% vs 26% in Figure 2).

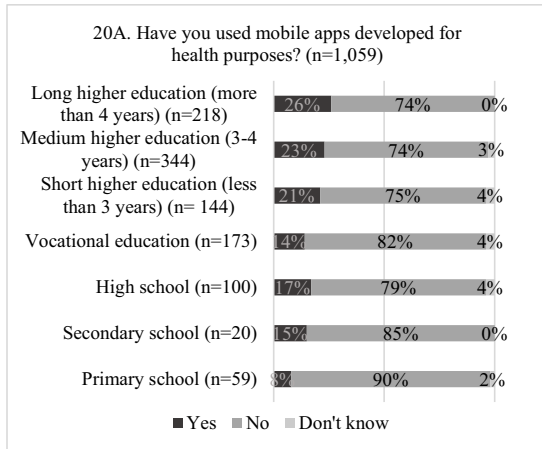


Figure2 - Cross Table: Educational Level and Expected Impact of Health IT

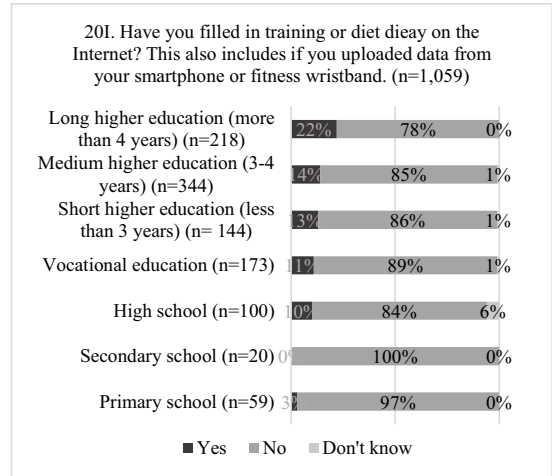


Figure 3 - Cross Table: Educational Level and Expected Impact of Health IT

Few citizens used Internet or fitness trackers to log information about training and food (30% n=1.059 in Figure 3). Also, here citizen with high education are more likely (22%) to use these services than people with low or only primary school education (3%).

The same is the case when asked about the use of Internet based self-help health services (6% low vs. 25% higher education in Figure 4).

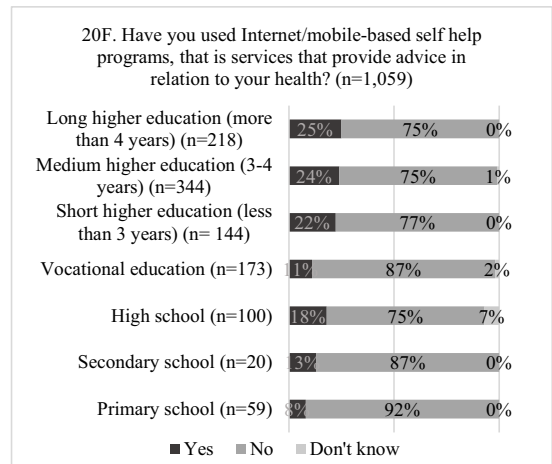


Figure 4 - Cross Table: Educational Level and Expected Impact of Health IT

The citizens with low education are less likely to ask questions about health and symptoms to healthcare professionals on the Internet (14% vs 23% in Figure 5).

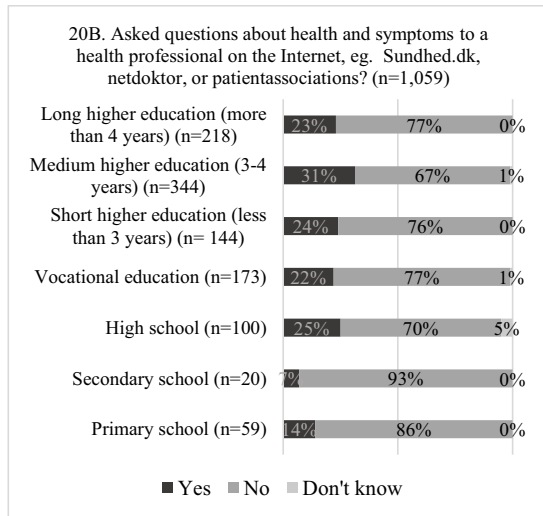


Figure 5 - Cross Table: Educational Level and Expected Impact of Health IT

When asked if they generally agree or disagree to the statement “I have difficulties navigating within health IT systems”, 26% with only primary school education agreed while only 14% of people with high education agreed (Figure 6).

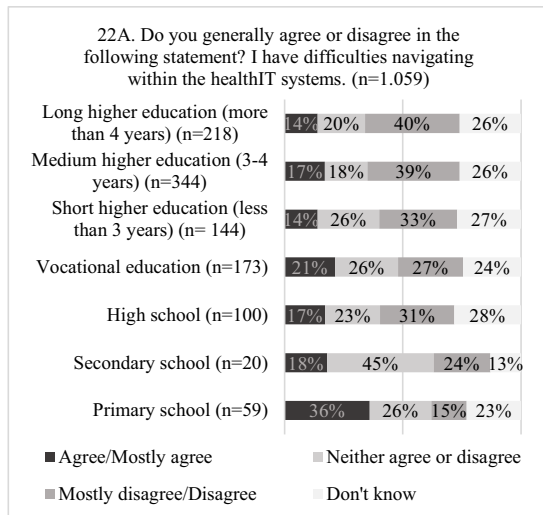


Figure 6 - Cross Table: Educational Level and Expected Impact of Health IT

Danish citizens are generally positive towards the use of IT in healthcare. However, the study shows that the higher the educational level, the more positive they are. As shown in Figure 7, there is high scepticism among respondents with low education when questioned whether they expected health IT to improve or impair the quality of the healthcare services they expect to receive within the next three years.

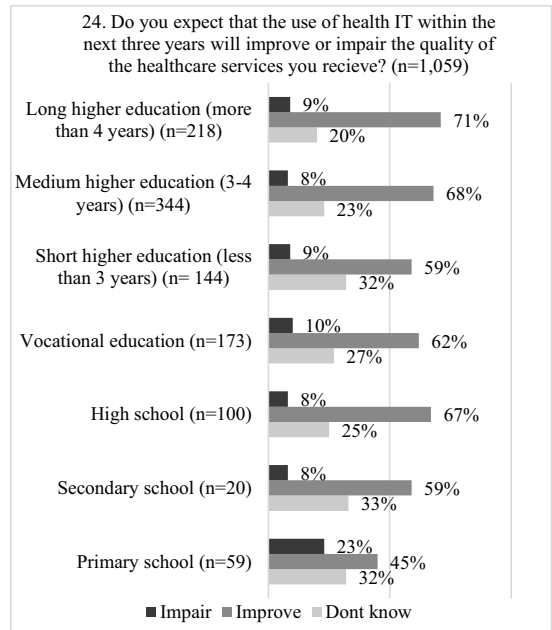


Figure 7 - Cross Table: Educational Level and Expected Impact of Health IT

Discussion

The study shows a significant difference between citizens with low and high educational level, when it comes to opinion on, knowledge of, and experience with the use of HIT and other Internet, apps or mobile services. In the answers, there was a significant tendency that people with low educational background are more sceptical, not so familiar with HIT and find it difficult to use the technologies and systems.

This indicates a strong need to target and support the socio-economically weak population in getting access to technology that can assist in accessing HIT and enrolling in DHI. The findings of the study empirically support the concern and conceptual framing of DDDs and PLU of Showell and Turner [17]. To address the findings, concerns as well as the challenges of health inequality in Denmark, attention needs to be placed on the role of the DDDs in HIT design, development, and use.

DHIs need to be specifically targeted at those citizens with the greatest needs if the digital and health divide is not to grow even larger. If the socio-economically challenged DDDs are to be given access to live a healthier life, it may have a positive impact on the health outcome and thus provide an economic benefit to the health care system.

To summarize this view, we propose (Table 2), that the problem be addressed both in relation to HIT developed to provide citizens with health data (C-PGHD) and DHI providing healthcare professionals with citizen and patient data (HP-PGHD).

Table 2 – Two Categories of Data Generated by Patient – and How to Handle HIT Inequality

Citizens - person/patient-generated health data (C-PGHD)	Healthcare professional - person/patient-generated health data (HP-PGHD)
Generated by citizens/patients for citizens/patients	Generated by citizens/patients for healthcare

Controlled and owned by the citizens/patient	professionals Controlled and owned by the healthcare professional
How to address health inequality in relation to HIT	
Provide special support to engage and involve socio-economically disadvantaged patients in design and use of HIT	Involve socio-economically disadvantaged users in Design (or re-design) of DHI-technology

The HIT technologies used to support such change need to be understood as not only technical but also socio-technical and therefore, designed and targeted with attention to the context of use and their future users. To point at what can be done to increase the equality, user centered design (where designers investigate what users need) [20] is believed not to be an adequate or sufficient approach to overcome the dominating PLU problem. Instead, we—knowing that this does not follow directly from the data in this paper—suggest technology designers to use a User Innovation Approach (UIM) [21]. Here users are motivated and encouraged by facilitators to develop design concepts that meet their specific needs (e.g. the DDDs specific needs). The designers of HIT and DHI need to hand over the stick to the socio-economically disadvantaged people (the DDDs) and by doing so for some time reduce their own professional role to (1) plan and facilitate, and (2) draft design concepts and draft prototypes to be validated and changed by the participants [22, 23, 6].

Conclusion

On the basis of an examination of the educational inequality detected in perspective on and use of HIT in a national Danish survey, we propose an increased focus on inequality in the use and development of HIT and involvement of citizens and patients from the socio-economically disadvantaged groups in HIT design and development. It will be of benefit to technology developers and the healthcare providers to improve the use of appropriate consumer HIT for this group, in both health care services and preventive health initiatives as well as general health monitoring and management in everyday life. Engaging with and involving this group of citizens and patients is important in levelling out inequality in health which is a key concern in a Danish healthcare context.

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Address for correspondence

Lone Stub Petersen, lonsep@plan.aau.dk.