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Fostering "Digital Subjectivity": An Investigation of Digital Health Narratives in Norway, the Netherlands and Czechia

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Introduction: Digital Narratives and "Digital Subjectivity"

The ability to share and access experiential information about health and illness offers a context for people with health and illness concerns to construct a "digital subjectivity" that profoundly affects what living with illness means. In the last two decades and across several countries in the world, digital repositories that carry such experiential information have been developed, as part of an effort to make health and illness narratives available online. The country-specific initiatives are all part of a larger

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effort, grouped together under the header DIPEx (Database of Individual Patients' Experience of Illness: see Ziebland and McPherson 2006), and all make use of a shared research methodology to collect and analyse peoples' illness experiences. The online repositories in each country are co-produced through close collaboration between people experiencing health and illness issues and researchers conducting a narrative interview approach to elicit the stories. Thematically grouped aspects of these narratives, resembling the illness trajectory people experience, are selected for online publication. The aim is thus to produce digital versions of the embodied person experiencing health and illness issues, which are accessible to a wide audience.

We think that approaching the merits of these online repositories from the perspective of "digital subjectivity" can successfully transcend the dualist categories "offline" and "online" and thus enable a more in-depth understanding of what it means to be ill in contemporary society. Both the academic literature and current health policies still fall back on the dual notions of "online" versus "offline" to describe which health information they think patients and carers need and where they would look for it (but see Mazanderani and Powell 2013, also Madianou and Miller 2012 and Ziebland and Wyke 2012). We aim to transcend this binary opposition to consider the online repositories in a society in which the division between online and offline is becoming increasingly blurred.

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Our research shows that digital practices are not to be seen as different from, but as an inextricable part of the everyday illness practices that constitute living with an illness for patients and for their carers. Examining the opportunities offered by digital technologies to represent illness experiences allows for a fuller understanding of how people make sense of the ways in which digital technologies and illness experiences can be linked and how they allow for developing particular illness-related identities as co-produced forms of knowledge (cf., Lamerichs and Van Hooijdonk 2019). Our contribution starts from the idea that we need to expand our understanding of how people with health concerns and their carers make use of such digital resources. Digital subjectivity offers us a way to supplement a predominantly informational perspective that concentrates on the way in which online illness experiences fulfil information needs. The concept of digital subjectivity sensitises us for experiences that go beyond the simple act of "collecting" information and helps to expand our scope to include the sense in which digital participation is actually formative of the illness experience itself. It can thus be understood to alter what the illness actually *is*. Our analysis of those who share their illness experiences online and those who visit or access digital platforms where illness repositories are hosted, challenges the point of departure in the literature emphasising how sharing objective, neutral, quantified health information affects the patient's role and the patient's relation to their doctor (Tan and Goonawardene 2017; Karnam and Raghavendra 2017). Our interest is in the (inter)subjective constructions of illness and identity in everyday lives, outside of the consultation room and doctor-patient dialogue. Hence, it is our aim to investigate how the concept of digital subjectivity can illuminate the myriad and interwoven nature of online-offline practices in peoples' experience and understanding of illness.

In what follows we present original empirical findings of interviews with patients and their carers that were held in Norway, the Netherlands and Czechia. To further substantiate the importance of a subjective understanding of the self in the knowledge landscape the World Wide Web poses, we present illustrative interview excerpts of how the interviewees talk about their needs when they try to come to terms with living with a particular illness.

Digitalisation, Digital Subjectivity and "Digital Prosthesis"

Over the last few decades, the interest in the digitalisation of health has grown in many academic disciplines, such as psychology, sociology, organisational studies, informatics and health sciences (Thompson et al. 2011). We explore what illness means as a "construction of digital and subjective formations". Based on our empirical findings, we will discuss if, and if so, how this angle can be of value to explain the complex co-constructions of digitalisation and subjective formations of health and illness in contemporary society, as well as to point to the use of DIPEx platforms as possible resources for such constructive practices.

Digital Subjectivity

Digital subjectivity has not been a much-used concept in studies of health and illness, but is known from other fields such as digital culture studies (Goriunova 2019), work on gaming culture (Charles 2009) and the domain of media studies (Giraud 2015). The concept of subjectivity has a long tradition and is central to both sociological and psychological research. Lately, subjectivity has been introduced as a theoretical angle to understand individuals' relations to digital tools as well as the potential to expand the limits of the self through "digital prostheses" such as mobile phones or personalised medical devices more in general (Rey and Boesel 2014; see also Lynch and Farrington 2018). In what follows we will mainly draw on conceptualisations based on the work of Rey and Boesel (2014) and Giraud (2015).

Rey and Boesel (2014) understand subjectivity as comprised of two equal elements: the body, or an embodied self, and the social conditions of the subject, that is, the historical conditions forming the subjects' social context. There are bodies and there is society. Their point is that both have changed through digitalisation. Embodiment is no longer just a matter of the self that is residing in organic flesh. Rather, today, we are also embodied through our *digital prosthesis*. Digital tools are prolonging

the expansion of our selves and can thus be seen as a new element to embodiment (Lynch and Farrington 2018, also Roberts et al. 2019). Further, the societal aspect that is equally central to subjectivity has also changed. The historical social conditions framing the lives of the individuals are no longer the same as for previous generations. Contemporary society is a digital society (Tamminem and Deibel 2018). Central to Rey and Boesel's argument is that the offline social context is neither more real nor more normal than the online context; the latter is just as normal and just as real, only it is new. Hence, both the embodied self and the social conditions of the subject have changed profoundly as we have moved from analogue to digital society. This change in turn causes new and augmented forms of being in the world, of subjectivity. Through this lens, digital subjectivity is not a restricted version nor does it replace subjectivity; rather it opens up new dimensions to it.

Giraud's (2015) approach to "digital subjectivity" stems from critical Internet and media studies. Her approach can be read as a critique of Dean's (2009) somewhat cynical conceptualisation of subjectivity in which users are believed to get trapped in never-ending communicative loops when they go online. This points to the risk that the business models of online information and communication services, based in machine learning, end up restricting and reinforcing the users' knowledge base rather than challenging and expanding it. This is of course an evident ethical and political problem. However, Giraud (2015) argues that there is a need to reconceptualise the digital subject away from such restrictive models and towards a more situated, material analysis of the *affordances* that become available by subjective entanglements with technology (Humphreys 2018). In line with Hutchby (2001) and Gibson (1979), we take the affordance of a technology to be "the possibilities that they offer for action" and acknowledge that these might appear different to different people and in different situations. Giraud (p.131) states that "A burgeoning body of ethnographic work, moreover, has suggested that the affordances of communications media are established through inter-subjective practice (cf., Madianou and Miller 2012; Cammaerts 2014; see also Couldry 2012) and emerge through their broader socio-technical milieu, rather than being intrinsic to the technologies themselves (Ash 2014)."

Subjectivity may be also understood as a perspective in which an individual appraises the world and his/her own self based on their current position in space and time, which is constantly changing or evolving (Gold and De Sousa 2012). The notion of digital subjectivity may also be seen as a way in which individuals approach and interpret their experience with digital media in relation to their position in the world. Neither digital subjectivity nor digital media are stable entities in time and space. Each person makes use of digital technologies or interprets the same information provided by digital spaces in a different way and makes use of these media based on their specific individual needs which might be emotional, social or educational in nature; they may also be driven by personal characteristics, or the abilities to understand and access the information provided in relation to the self (see also Madianou and Miller 2012 for a discussion of media and communicative intent). Furthermore, and similar to other prostheses, affordances of the digital technologies to the users are given by their perception, which will influence their practical usage of these tools. We were interested in how people dealing with specific health conditions make use of digital technologies: what affordances, or possibilities for action, do they realise; is it used as an information source, as a prostheses or as both at the same time?

Methods

In this chapter, we present a secondary analysis of a total of 89 narrative interviews from three national studies concentrated on health and illness experiences. The interviews were selected from a pool of interviews carried out as part of DIPEx research conducted in the three different countries and were concerned with different health concerns: muscular disease; chronic nightmares, complex pregnancies and dementia. We will report on findings found in 5 interviews conducted in Norway, 30 interviews conducted in Czechia and 54 interviews conducted in the Netherlands. The interviews were conducted between 2012 and 2018. The aim of including such a varied selection of narrative interviews on illness experiences is that it enables us to highlight common features in the

co-construction of illness and digital participation across countries and health challenges.

Description of the Data

The researchers who shared data and co-authored this chapter all participate in the international research network DIPEx (Ziebland and McPherson 2006). DIPEx International was founded to promote the spread of robust data conveying people's experiences of health and illness (DIPEx International 2020). The members of DIPEx International use the DIPEx methodology which aims to (1) promote excellence of qualitative research into people's experiences of health and illness, (2) advance the use and application of the results of this research to inform and improve health and health care and (3) support cross-cultural comparisons of people's experiences of health and health care and encourage appropriate action of the findings.

Analytical Approach

Our approach intends to pursue whether the empirical findings we present illustrate the notion of digital subjectivity to illustrate that the illness repositories, for both the people who tell their stories and the people who visit them, are not only concerned with gaining information. We propose that a purely informational perspective does not suffice to explain what we see and argue that our empirical data show that "digital subjectivity" is treated as an affordance of the online DIPEx repositories. In line with the work by Lucius-Hoene, Breuning and Helfferich (2018), we present evidence that this affordance is experienced both by the people who share their story in these repositories and for people who access the repositories in different ways. The empirical chapters will be concerned with present findings from three DIPEx repositories in Norway, the Netherlands and Czechia.

For the analysis we scrutinised our data for examples of how narratives shared through health talk websites can represent *digital prosthesis* of the

narrators and thus be understood as formative for the participants' digital subjectivity. We will also report some preliminary findings on how people who access online repositories (i.e. secondary users) relate to these narratives and how they include them as part of their lived experiences. We posed the following questions from our data:

1. Can the narratives produced and shared in the different DIPEx repositories be understood as digital prostheses and if so, in which way?
2. How does the extension of the body to also include digital forms, like voice, film or text matter for constructing individual experiences of health and illness?

In sum, we propose that digital subjectivism is an interesting and fruitful lens to the lived practices involved in "accessing" online health experience. We will illustrate this with examples from DIPEx research in three countries. We will now turn to our empirical materials.

The Participants Who Choose to Share Their Narratives: Findings from Three Studies

In this section we present examples from three countries that illustrate our main claim(s) about digital subjectivity and prosthesis.

Embodiment: The Norwegian Account of Muscular Disease

In Norway a small pilot study (five participants) was conducted among people with rare muscular diseases. One of the participants, a 36-year-old man, told us that he had been severely ill since he was 11 years old, but only when he was 30 did he meet a doctor who diagnosed him. Before that he had been in and out of several institutions and met both specialists and general practitioners who had not been able to come to any conclusions about the disease he was suffering from. Our informant had been in a wheelchair for years. Over the last 25 years, he had been ill and

he had been experiencing increasing limitations in muscular function in his hands and fingers. When we met with him, he could not write. Another symptom of his illness was hearing loss. In the following quote, he explains about his subjective experience of the illness after he was being diagnosed and discovered there was a patient association for people with muscular disease that he could participate in:

Participant 1*:* "After I participated in a course (arranged by the Norwegian patient association for muscular disease), I accidently read the participant list and some of the papers and realized that one of the other participants had the same diagnosis as me. I e-mailed her through Facebook. That was the start of our friendship. We have chatted a lot online, sent SMS messages and so on. Most of the communication is online when I talk to my friends. I cannot talk on the phone."

Interviewer: "When you say that you chat online, do you receive help for using the keyboard? Or how do you do that?"

Participant 1: "No, I can do it by myself. That is; I use only my thumb. I can experience it as tiresome, so in fact I always express myself in the short. You could say I use a lot of time for this."

Another informant from the same study was in a wheelchair. She explained her feeling of being an outsider:

Participant 2*:* "What bothers me most about being ill, is that one cannot mix into society, but is left outside and gets extra notice. You know, sometimes people look a little bit afraid when they see my wheelchair. They are terrified of bumping into me and shy away already one meter away."

Our interpretation is that these two participants experience their illness in and through a digital everyday life, and the characteristics of digital communication must be acknowledged as formative of their subjectivity. These examples show how both elements of subjectivity in

Rey and Boesel's theory ([2014](#)), the body and the social conditions, are mediated and given new form by engaging with the digital domain. Embodiment is not only about the organic flesh but also about what the body can perform through digital prosthesis, like a keyboard in the case of informant 1 above. Through this digital prosthesis, the limits of his body and hence its social agency are both confirmed and enabled, conveying a sense of affordance. The Internet, in combination with the keyboard he can operate with his thumb, opens up a new avenue for social participation.

The story of the second participant is a concrete example of how historical and social conditions frame the subjective experience of illness. While not referring to the online domain, our interviewee explains how other people's reactions to her sitting in a wheelchair is a matter of concern for her. Wheelchairs are stigmatised as deviant. As was also referred to by the first participant, the digital domain is described in terms of enabling factors rather than in terms of exclusion and in term of factors that render the social stigma less prominent and less constitutive of the illness experience.

Encountering a Normalising Frame: The Czech Study of Chronic Nightmares

In Czechia, 30 adults were interviewed, of which 22 were female and 8 male. All participants suffered from chronic nightmares and had at least one disturbing dream per week. Interviewees were recruited through various communication outlets and from different parts of the country. In order to create a sample with maximum variation, people with various experiences were involved in the study. In this instance, it involved people who were undergoing different types of therapy, people who varied in frequency and severity of their nightmares and people reporting different causes or accompanying conditions (e.g. sleep paralysis, insomnia, anxiety or depression). The purpose of this study was to explore how individuals with frequent nightmares use the Internet in relation to their chronic nightmares. For the current purpose, we undertook a secondary analysis to relate the interviewees' stories to digital subjectivity.

Out of 30 participants, more than half said they searched the Internet in relation to their nightmares to find information. Participants were typically interested in causes of nightmares, possibilities of treatment, the meaning of their dreams (dream dictionaries) and information on accompanying sleep problems such as night terrors or sleep paralysis. There were also secondary aims involved in what seemed to be a straightforward information need: one of the participants was relieved when the information she found online helped her to find out that symptoms she suffered from (muscle paralysis, hallucinations of demons, etc. before awakening) can be found in sleep paralysis, which is quite common in the general population. She experienced a normalisation of her own symptoms when she realised that other people have the same experience and this even has a name. Such normalisation may not only result in immediate relief but may also have an effect on one's perception of self and how one understands herself or the world:

Participant 3: "I really believed it was there (demon) and I was afraid of looking under my bed. After I found that many people have the same experience and that it is caused by a dream or by a sleep issue, I don't believe it was real anymore."

The power of online information to change the subjective perception of illness and one's self-perception was emphasised by three participants, who rather did not search for information on nightmares on the Internet anymore because they were afraid of worsening their state. They said that some suggestive information might make them feel bad about themselves or they might start to believe there is something wrong with them.

Participant 4: "I don't seek information online anymore because (…) it might make people to start believe they are not alright. Someone online says that something means something and I tell myself 'dang it, it is me! That is terrible!'".

It seems that in comparison to informant 3, who experienced normalisation, informant 4 was worried of experiencing de-normalisation. We may say that digital subjectivity depends on personal interpretations of

the information and it is highly contextualised (see also Lynch and Farrington 2018). Individuals' diverse experiences with the illness, symptoms, their own personality, life situation, worries or self-perception influence their interpretations; some of these interpretations help them to cope with their illness and others do not. Importantly, digital subjectivity is not a fixed state, nor does it only pose positive added uses when encountering the digital. The interviewees illustrate this by showing how these sources of information are open to diverse interpretations and discussions of relevance and trustworthiness. One additional example of these multiple interpretations is when interviewees address the topic of "passive digital participation". Interviewees reported to seek stories told by other people with the same concerns which brought them relief. A female participant used social networks to hear about the experiences of other people, but she did not tell the researcher she would share her own experiences. Digital participation may even be formative even if users only listen to experiences of other people with health issues and do not share their own story.

These findings illustrate the broad range of affordances and limiting factors of the Internet for people experiencing frequent nightmares. As an important positive aspect, the online information offered relief in the sense that they are not alone and provide a normalising frame to consider that what they are experiencing is "normal".

A Vocabulary to Convey Subjective Meaning: The Dutch Experience of Living with Dementia

The 48 interviewees who were interviewed for the DIPEx dementia in the Netherlands were all informal carers who cared for a loved one who was experiencing the onset of dementia. In the interviews they point out that they were quite satisfied by the possibilities the Internet offers to search for information about the illness and the many sources that address dementia in particular on different websites. They also point out that they are able to find the information they need and have some sense of discriminating between what is trustworthy information and what is not. A downside they reported on had to do with the use of technical language

to describe aspects of the illness, which was considered unclear and limited the accessibility of some information sources.

Participant 5: "[…] You can read a lot and interpret it and well, how do you interpret whatever it says there on the Internet? Often it is medical jargon, terminology that does not speak to me. But what it says, what it means, could still have a big impact."

At the same time, interviewees expressed a clear need for a different type of information they also considered lacking, that is, experiential information on how to live with (someone with) dementia, given that there is no cure for the disease, as participant 6 points out.

Participant 6:   (carer for father-in-law)

"Uh yes I find it really horrible that there is no cure. Uh and there is research or something that slows it down the progress of the disease. [–] But it wasn't clear to me at all that was such a hopeless situation. Uh I have, yes wished that I could go somewhere, that I, zap, there is a cure, that can relieve the disease or something. Ehm that was such a blow. And then I have changed my search to uh, to the other side. How can I manage to be with someone who is so seriously ill. How can I help him, emotionally, love him, all those things. Then uh, yes I explored that side, not the medical side but managing to live with the diseased person."

The interviewee below is being asked also to talk to the information she/he thinks is missing in what she is reading on Alzheimer's disease (in addition to recounting her experiences in seeking for help or support for her family member). She states that there is an abundance of technical information available, but that what is missing is the variability in experience and information for friends and relatives on how to be around someone with dementia.

Participant 7: (carer for spouse)

"It is not a uniform package this, so you have to […] And you can't make any plans for the future because nobody knows exactly how it will go, what will happen and that is true of course for everybody's life [pause 4 sec] But uh I think that for example friends and relatives don't know how to be around someone with Alzheimer's, how you could be around someone [pause 3 sec] because yes there is little information available, in whatever way, for them on how to do that, deal with that."

The Users of Illness Repositories: Findings from Two Studies

To expand our understanding of how patients use the DIPEx narratives, we have been able to explore the experiences of two groups of users of the repositories. This section reports on the findings of a study conducted in Czechia in which 9 of the 30 participants talked about what they would expect from a DIPEx repository on this topic. We also report on a study conducted in the Netherlands involving pupils who learned to become nurses caring for people with dementia. They accessed the online illness repository in an educational setting, in an attempt to close the gap between what pupils learn about dementia in theory and the people they care for in practice, offering a particular contribution to improving communication skills when caring for people with dementia and their families (Lamerichs and Alma 2018).

Availability and Accessibility as Drivers of Awareness

One of the benefits participants speak about is the importance of raising awareness, in multiple ways. For those who do not suffer from nightmares themselves, it can help to understand those who do suffer from frequent nightmares. Participants also stated that people who frequently experience nightmares might open up to other people more and start

talking about their experiences. According to another male participant, the website could also help those people, who have no one to talk to about their issues: it may help people who can't or don't want to talk about their problems but still seek support.

Participant 8*:*   "It will help these people to open up and tell what they want or what they needed to say."

Another female participant liked the fact that the repository would contain stories of real people and would therefore not be totally anonymous: "I know that there are others with nightmares, I know what they look like and I can picture them concretely."

If we think about the repository as prostheses, as an enabling technology that helps to understand and manage illness, the very fact that it offers patient experiences in recognisable and therefore accessible language is important because this would enable access and use and an important means to relate to the experiences that are addressed in the repository. Importantly, interviewees consider this to be lacking, currently.

Participant 9:   "What I miss is a website with comprehensive information based on fact that would be accessible for a lay public (17)."

Learning the Language of Lived Experience

Online repositories can also offer a vocabulary to talk about the illness, as was shown in the Dutch case (see Lamerichs and Alma 2018 for a full account). The Dutch case illustrated how pupils who were taking courses in dementia care in secondary vocational education in the Netherlands showed that the experiential digital narratives of people who experience the onset of dementia offered them a language to use when communicating with the carers of people with dementia. They also considered it as a unique means to access the lived experience of the person with dementia, as the following excerpts from the educational pilot carried out in the study show:

Participants 10:   "It hits closer to home you know to have people—not theory because these people tell it themselves and also you know the lady who told how she felt when her children entered the room they can describe it best you know, what it is like."

The people who experienced the onset of dementia and who were interviewed often made use of vivid anecdotal language and metaphors. Pupils picked up on those metaphors and quickly incorporated them in their own language in class interaction and stressed how useful these metaphors could be to use when talking to relatives, who experienced difficulties understanding that their loved one could experience better days and days in which she felt worse. One woman with dementia used the image of a knotted little ball of wool as a description of how her head felt in the morning and which worked to indicate whether her day would be good or bad, or how it could sometimes also gradually improve, which she compared to finding the beginning of a thread in the ball which would help her untangle it. After hearing about this way of describing this, as an example in the online repository, the pupils discussed with their teacher about its importance in explaining the different states family members sometimes find their loved one in, when entering the care home, without understanding this difference to a full extent: it sometimes even posed problems. To be able to explain to the family members how their mother might be feeling, by using the metaphor she used in her own words, was considered very helpful. It offered them an actual vocabulary to communicate some of these thorny issues and to explain for these apparent differences and learn to read the signs on how their mother might be feeling.

Participant 11: "(..) and next time they might have found a string that runs and then they are able to talk about all kinds of things so then for the family you know for example then they are very well able to talk with their mother about all kinds of things and if it turns into a knot all of a sudden then it is completely different so then when the children enter the room then it is like ah well how is my mother doing today?".

Concluding Remarks

The question of how digital technologies matter for the construction of health and illness in contemporary society needs to be properly addressed. We have entered this discussion in this chapter through the concept of digital subjectivity, to highlight the potential of online participation to expand and alter the performance of illness and health practice in people's everyday practices. Looking at the co-construction of illness and digital participation across countries and health challenges, and through the lens of digital subjectivity, allowed us to illuminate how the particular entanglement of (a) living with health challenges and (b) using tools for digital participation in everyday life, affects the lived experiences of health and illness in contemporary society.

We identified three aspects central to subjectivity formation that are relevant to the production and/or use of digital narratives: embodiment, normality and language. For persons living with illness, these are all integrated into their daily illness practices and thus their subjective construction of illness. For our participants, the distinction between online and offline practices with respect to these three narratives was irrelevant; rather these seem to overlap and are interwoven in their daily lives.

In the literature the objectifying effects of digitalisation have had a strong prominence over the last years (Goriunova 2019; Roberts et al. 2019). Discussions have arisen on how digital tools contribute to the emergence of self-tracking cultures contributing and constituting a "the quantified self" (Lupton 2016; Lynch and Farrington 2018). These studies highlight how computing and digitalisation allows for the monitoring and storing of large quantities of biometric data on individuals, data that in turn can be used by the individuals themselves, or by second or third parties as population statistics. The availability of digital tools increasingly available to health professionals (i.e. the electronic patient record) adds to the same development: the creation of big datasets on population health. The debates that surround these developments exemplify how the digitalisation of health and the construction of the digital subject in terms of data profiles and big data contribute to a strengthened objectification of the individual. A negative side effect of these developments and debates

is that it leads to a neglect of individuals' subjective experiences and health practices in the digital domain, which are of central importance for people experiencing illness, their carers as well as people in caring professions.

Our work has attempted to illustrate the importance of supplementing the stories of digitalisation as objectifying statistics and driven by information per se. We have highlighted some of the other stories that can be told about the co-construction of digital society and illness. Digitalisation opens up a resource for individual patients that contains stories about health and illness to be shared in new ways. The digital subject can also be "captured" via objectivisation by commercial interest, as already noted in the introduction to this book, but this has not been the focus of this chapter. We have attempted, as has Giraud (2015, but also see Goriunova 2019: p.127), to examine the digital subject through a micro-level, material analysis of the affordances enabled by digital tools.

We also want to emphasise that we need to go even further when discussing the digital subject. As with other stories, patient's individual narratives can now be stored and travel faster across time and space. They too can have an existence of their own, independent of the storyteller and open for second or third parties to interpret and perhaps exploit. There is a need for more research on how these practices will affect individual experiences of health and illness, as well as how it can be organised to be of benefit to patients, for health care personnel and for quality improvement in the health care sector in general.

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