

M. Strano, H. Hrachovec, F. Sudweeks and C. Ess (eds). *Proceedings Cultural Attitudes Towards Technology and Communication 2012*, Murdoch University, Australia, 199-211.

IN/VISIBLE BODIES

On patients and privacy in a networked world

MAJA VAN DER VELDEN
University of Oslo, Norway
majava@ifi.uio.no

Abstract. In the networked world, privacy and visibility become entangled in new and unexpected ways. This article uses the concept of *networked visibility* to explore the entanglement of technology and the visibility of patient bodies. Based on semi-structured interviews with patients active in social media, this paper describes how multiple patient bodies are produced in the negotiations between the need for privacy and the need for social interaction. Information technology is actively involved in these negotiations: patients use technology to make their bodies both visible and invisible. At the same time technology collects data on these patients, which can be used for undesired commercial and surveillance purposes. The notion of *visibility by design* may infuse design efforts that enable online privacy, supporting patients in the multiple ways they want to be visible and invisible online.

1. Introduction

Many years ago I visited my friend, who was a professor at a university in another country. He had told me he would wait for me at the entrance. He was there when I arrived. We greeted each other and then he told me to hop on his mobility scooter because his office was at the other end of the building. While we moved through the corridors of the university I suddenly realized that people were watching us. What began as a private arrangement between two friends had become a public spectacle – at least that was how I interpreted the way people looked at us. I was reminded of this experience while reading Jeannette Pols (2010) article *Breathtaking practicalities: a politics of embodied patient positions*. Pols discusses in particular the role of mobility scooters in making people with Chronic Obstructive Pulmonary Disease (COPD) visible. Why did people stare at us? Following Pols' line of thought, I can see how the scooter made not only our bodies, but especially our contrasting bodies visible, as we differed not only in ability, also in age, size, gender, and ethnicity. If I had walked next to the scooter, I could possibly have been a foreign student meeting her professor. The fact that I shared the scooter with my friend changed everything.

Pols uses in her article the terms visibility and invisibility, with invisibility as a metaphor for the absence of disease in any form (p.194). Some of the patients in Pols'

article felt misunderstood because their disease is invisible. Some thought that using a scooter would make their disability visible, but, as Pols describes, what became visible was the scooter, not their disease. Some patients could walk a bit on some days but needed the scooter on others, but on all days their bodies were not visibly disabled.

For the past two years I have studied how patients negotiate privacy in social media. Patients are active users of the Social Web: they participate in online patient communities, they write blogs, they use patient portals to communicate with health care personnel or to report their medical data, and they meet up with other patients in social networks. Mobility scooters made patient bodies both visible and invisible - what about social media? How do social media make patient bodies visible and how do patients use social media to make their bodies visible or invisible?

In *Missing Bodies: The politics of visibility*, Casper and Moore (2009) write that the human body has never been more visible than in the first decade of the 21st century. Our visualized bodies are under surveillance, are digitalized, and processed for analysis (ibid, p.2). But some bodies are invisible, missing, not accounted for. In the context of privacy, the *visible body* and *invisible body* are often understood as the public and private body. Invisible bodies are thus not understood as missing bodies, they are seen as private bodies. The idea of the invisible body as the private body fits within a particular privacy understanding: privacy can be read along a privacy-disclosure axis, in which more disclosure means less privacy and vice versa.

In the study of privacy as a practice, privacy is not solely something an individual owns – or has a right to – but an outcome of sociotechnical arrangements. As I will discuss in this article, when looking at the practice of privacy, other bodies become visible, such as the *patient body*, the *regular body*, *objectified body*, *exposed body*, the *quantifiable body*, and the *protected body*. Secondly, it becomes clear that these bodies are situated in time and place. What is visible or invisible at one time or in one situation, can be different in the other. This complicates design efforts: how to design for privacy when we have to take into consideration a patient's multiple and changing body positions and multiple privacy needs.

The remainder of the article will be as follows. In Section 2 I will discuss the relation between privacy and visibility. In Section 3 I will present my research in the *Patients | Privacy | Internet* project and present some extracts from the interviews I conducted with patients. In Section 4 I will look closer at the visibility and invisibility of bodies at the intersections of patients, privacy, social media, and information technology. In the concluding section I will reflect briefly on the in/visibility of bodies and technology design.

2. Privacy and Visibility

In a world replete with images and representations, who can we not see or grasp, and what are the consequences of such selective blindness? [...] questions about optics are inescapable. How is visibility possible? For whom, by whom, and of whom? What remains invisible, to whom, and why? (Haraway, 1997, p. 202)

The relationship between privacy and visibility has been theorized in different ways. When Hannah Arendt wrote about visibility and invisibility in the public and private sphere, she pointed out that there was a good way and a bad way to be visible. It was good to be visible in the public sphere, but bad to be visible in the private sphere. Public visibility and private invisibility are complementary: privacy makes visibility in the public sphere possible (Borren, 2008).

Michel Foucault (1977) said about visibility without privacy: “Visibility is a trap” (p.200). Writing about Bentham’s *Panopticon*, Foucault argues that modern society assures its power and control through permanent visibility of its inmates, patients, insane, etc. Donna Haraway (1997) argues, however, that the *adverted gaze* can be as deadly as the all-seeing panopticon: “Not counting and not looking, for example in health and well-being, can kill [...] as surely as the avid seminal gaze of state security [...]” (p.202). Here invisibility does not necessarily means privacy, but implies not to be taken into account, *missing*.

In social media, such as blogs and social network sites, the relationship between privacy and visibility becomes tangled in new ways. For example, Kim (2008) talks about the private space of public blogs. Boyd (2007), Livingstone (2008), and Steeves (2010) write about teenagers seeking privacy from their parents in social network sites. The affordances of the technology underlying social media complicate how we think about privacy and how we do privacy (Palen & Dourish, 2003). They also complicate answering Haraway’s critical questioning of visibility: “How is visibility possible? For whom, by whom, and of whom? What remains invisible, to whom, and why?” (1997, p.202).

In order to address this entanglement of technology and visibility, I introduce the concept of *networked visibility*, Felix Stalder’s (2011) sociotechnical perspective on visibility. Networked visibility “is created by the capacity to record, store, transmit, access communication, action and states generated through digital networks” (ibid). People become visible in and through the data they share in digital networks. The features of this data are, according Stalder, *durability*, once recorded it can be available for a very long time; *highly transmittable*, it can be available at different places and at the same time; and *no scale limit*, the data is easily aggregated and de-aggregated.

Stalder argues that social action always requires visibility. This visibility is horizontal, such as the visibility in social networks, where people who befriend each other obtain access to each other profile information. *Horizontal visibility* creates trust and is based on weak cooperation, which explains the ease with which people connect and form groups or cooperate voluntarily. The opposite of horizontal visibility is *vertical visibility*. The crucial technical factor in vertical visibility, argues Stalder, is that computers produce records of their own states and actions. The providers of these computers, e.g. Google or Facebook, can make everything that’s happening on their systems visible, independent from the privacy policies governing those systems. In addition they sell access to third party applications that aggregate data for commercial ends. These ends are quickly expanding, from targeted online commercials to fine-tuning medical insurance.¹ Vertical visibility makes visible what was hardly ever visible before, but what becomes visible is not necessary public information. These systems,

¹ See <http://www.celent.com/reports/using-social-data-claims-and-underwriting>. Retrieved January 25, 2012.

Stalder argues, can thus make social dynamics visible and advance or block them, without anyone knowing: “This type of vertical visibility creates new centres of networked power that are, so far, outside any democratic control”. Stalder therefore calls for a politics of visibility, which promotes horizontal visibility and limits vertical visibility. The notion of privacy, he argues, is unproductive in such a politics of visibility: we need infrastructure projects that reverse the trend for centralization and vertical visibility.

2.1. VISIBILITY BY DESIGN

Instead of doing away with the notion of privacy, as Stalder suggests, I will argue in this paper that understanding privacy, by studying the practice of privacy, will contribute to infrastructural projects that take the multiple privacy needs of its users into account. Stalder’s conception of privacy seems based on the idea that privacy is withdrawal from the public. Any disclosure, to increase horizontal visibility, produces vertical visibility. Research on privacy behavior on the Internet shows that users negotiate privacy within what Stalder calls horizontal visibility, but do not take into consideration what disclosure may mean for their vertical visibility. This phenomenon is often called the *privacy paradox*, users say they care about their privacy, but they don’t act on that concern (Acquisti and Gross, 2006; Barnes, 2006; Norberg, Horne, & Horne, 2007; Radin, 2001).

The privacy paradox becomes less of a paradox when privacy is understood as multidimensional (Burgoon, 1982; Burgoon et al, 1989) or when privacy is conceptualized as a dynamic and dialectic boundary regulation process (Altman, 1975; Petronio, 2002). Building forth on Altman, Palen and Dourish (ibid) focus on the ways in which information technology disrupts or destabilizes the regulation of boundaries. These perspectives are more appropriate for addressing Haraway’s critical questioning of visibility. Research taking a multi-dimensional privacy perspective shows that people do care about their privacy, but can not always act on all concerns (van der Velden & El Emam, in press). These insights enable us to contribute to infrastructure projects that are concerned with both forms of visibility. They help us to deal with the risks of vertical visibility, the undesired visibility of our personal information to people and systems unknown to us. They help us to support the multiple and diverse ways in which we seek horizontal visibility, the desired *visibilities* of our personal information to people with whom we want to socially interact.

3. Patients, Privacy, and Social Media

Patients / Privacy / Internet is a qualitative inquiry into how patients perceive and do privacy online. The results of this study will contribute to a larger project in which we study the different configurations of autonomy and automation in order to contribute to new understandings of human autonomy as well as to the design of public sector information systems.

This paper builds forth on research implemented in Norway and Canada. In Norway I have interviewed adult patients active in social media. These patients are

selected because they maintain a patient blog besides their Facebook account. I follow these patients over a long period. This includes becoming their *research-friend* on Facebook. In Canada I have interviewed teenage patients in a children's hospital (see (van der Velden & El Emam, in press). These teens were between 12 and 18 years old and were chronically or long-term ill. The patients had accounts on Facebook, but I did not become their *research-friend*. In the following sections I present extracts of semi-structured interviews with four of the study's participants.

3.1. "THE HECK WITH PRIVACY"

Mari (pseudonym; in her sixties) started her blog immediately after she received her diagnosis. This was the first time she got involved with social media. She had read about it in a newspaper and thought it was a good idea. She knew she needed all her time and energy to get better and to get on with doing things that would give her energy. Explaining everyone over the phone the bad news did not fall into that category. Writing a blog was not ideal, but it had one big advantage:

"On a blog you write it once and you don't have to talk about it anymore. I did not want to repeat the negative news over and over again".

Mari wrote her blog for the people she knew. She used her own name and profile picture. About the idea of not using her name she says:

"It feels like cheating. I feel like I don't do anything I can't stand for. That is basically my gut feeling.

How she wrote in her blog developed over time:

"Other parts of life tend to seep in. I think that's what happens. Also, in the beginning I mention everybody by name. [...] I try not to do that any more. I have become much more conscious about it."

Since Mari's blog was publicly accessible on the Internet, she also started to receive comments on her blog postings from people she didn't know:

"It became as a big surprise for me that other people found it and wanted to read it. I didn't expect anyone to take an interest in it. Even for the people who knew me it came as a surprise: O, you are so open and you are so [personal]. And I deliberately write it down as neutrally as possible what was going on without ... I did not want to be very emotionally about this. I wanted people to have information. Also, there is another function to that, I realised afterwards, that it helped me to remember what had happened."

Mari was not concerned about her own privacy. She wrote openly about the different side effects of the therapies she received, discussing how certain parts of her body and their functions were affected. She had strong opinions about privacy in the healthcare sector. In her opinion, Norwegian laws and policies unnecessarily delay the communication between the different hospitals and specialists, because digital technologies are not allowed for patient – healthcare provider communication and medical staff in one facility has no online access to her medical information digitally stored in another medical facility:

“As a patient I say: the heck with privacy - as long as it works, I don’t have time to wait for all the caution. I am ill, I could die, you know. I want to be treated, I want to live. [...] Intellectually I can go above my feelings as a patient and say: Of course privacy is something important. I do see that, but within my patient realm, I am much more impatient”

Mari felt that at least in her blog she had some control over privacy issues:

“I developed slowly the way I think about it. I stopped giving names to the people that were close to me, but I started giving the names of the people who were treating me.”

But Mari experiences this control as relative:

“For a private person, it seems like a sort of existential dilemma. No one should be on Facebook or have a blog if we think about how the information could be misused. It seems a process you ... you can’t stop it by not attending.”

After Mari started her blog, she realized that people would get worried if she didn’t write regularly. This was different with her Facebook account, which she started a year after she started her blog. She uses her Facebook account purely for social things. She doesn’t feel any responsibility for informing people. She enjoys reading what other people post, often things she wouldn’t know if they hadn’t written it on Facebook.

Mari is not interested in reading other patients’ blogs or Facebook messages:

“I am not interested in illness; I just happened to be ill. I am not the illness. It is not me. When I first became ill, I wanted to see people because I wanted to know what they were doing in the world. I certainly didn’t want to talk about my illness. I have to deal with my illness. I have to deal with learning about it and treatment. It is a job, but it is not a career. It is not what I like to do. [...] I met some patients who are very depressed: they feel very sorry for themselves. They make their illness into their career. I wanted to do things that gave me happiness and life quality. [...] I try to avoid it because I don’t want to be exhausted from other people’s problems”.

When I interviewed Mari she told me she was very ill and she did not know if she would get better. At a certain point she stopped writing her blog. A few short messages on her Facebook wall brought her life as a patient into her Facebook social network. Then the sad announcement came that she had passed away. Her Facebook site has now become a place for condolences, mourning, and memories. A couple of months have passed and some of her friends use her wall to communicate with her. They send her ☹s or tell her they think of her. One friend mentions she is glad that her profile is still active as it is like a grave she can visit from time to time. Visibility has now become symbolic.

3.2. “TO HELP OTHERS, YOU NEED TO SHARE PERSONAL INFORMATION”

Stein (pseudonym; in his fifties) was active on Facebook. He decided that after he had undergone a big operation, he would blog about his recovery. Stein’s blog is written for people he doesn’t know – people who are struggling with the same problem he had and who are contemplating the same operation. Unlike his Facebook account, which is only accessible to his Facebook friends, his blog is public, accessible to every one on the Internet. He has posted photos of himself in which he shows himself before and after

the operation. More than a year after the operation, he continues to give updates about his recovery, including details about his body, the things he needed to learn, and the joy he still feels of having undergone this life-changing operation:

“I am no longer ashamed about myself. I have overcome that feeling. Since my youth I had a very bad self-confidence. I had to work myself through many processes. I am now more self-assured. I feel the need to tell others, who are maybe new to this process, that it is nothing to be ashamed about. That I can help others, that is my great wish. But to help others, you need to share your personal information. You have to be open and honest, so the readers get the message that this is real. If I hide things, readers will be skeptical.”

Stein expresses his newly won self-confidence by being visible, both in words and in photos about his body:

“I am no longer shy - I was. By posting it all [on the blog] you overcome an obstacle.”

It is however important for him to stay in control. He doesn't want people to copy or tag his pictures:

“My message is from me to the readers [of my blog], not from one of my readers to a third reader.”

3.3. “NOT ALL MY FRIENDS NEED TO KNOW”

Amy (pseudonym; 17 years old) has been in the hospital for the past seven weeks for treatment of a rare disease. She is lying in bed, connected to an IV. Amy is an avid Facebook user, but she also has an account on Upopolis², a closed social network for young patients in Canada. About meeting other patients in Upopolis she says:

“It is a great network to talk to other patients who have the same diagnosis as you. So, since I am new at this, people that are not can explain how they dealt with it.” [...] “It was nice to see that you are not alone”

Amy did not write a status update on Facebook when this hospital stay began:

“I never wrote something about my diagnosis because it is not people's ... like they don't have to know. I tell my friends in real life, like when I talk to them in person, but not on Facebook.”

“It is just ... if I want to tell someone, I will tell them. Not all my friends need to know, you know.”

But in the beginning she told even less friends:

“At first I was more private about it because I didn't ... I was still in the acceptance stage you know, but now I am pretty open about it when people ask me. I am not going to scream it to everyone, I wait until someone wants to know. I am not ashamed of it.”

² See <http://www.upopolis.com>. Retrieved February 27, 2012.

3.4. "THERE IS NO CLUE THAT I AM SICK"

The last patient I introduce in this paper is Eric (pseudonym; 17 years old), who has a long-term illness. He has been in and out of the hospital for the past two years. I meet him when he is visiting the day unit where he undergoes some blood tests. He uses Facebook daily, but his favorite thing to do on the Internet is to play the Game. His parents are also playing the Game and they know each other's avatars. Sometimes they form a team and play together. They also teamed up together when their son was lying in his hospital bed. When they play, they don't ask him how he is doing:

"No, no, they play their role. I am as equal as they are."

"They know that I don't like being put down ehhe like be reminded that I am sick. I just want to try to live without thinking about it, you know, like everyone else. I try to be like everyone else, as somebody normal."

Also on Facebook Eric is not presenting himself as a patient:

"No, there is no clue that I am sick."

But Facebook is handy when you are in the hospital:

"It is to keep in contact with my friends. Yeah, it is, it plays a role in helping me because I can't really go out and play as much as I was doing before I was sick. It is a way of staying in contact with my friends."

He also uses Facebook to store his pictures, but there are no pictures from the hospital on Facebook:

"I mean it is like ... I don't know ... showing my weakness. I would not show that to anyone."

He communicates through Facebook's private message system which functions as his email. When he has day treatment in the hospital, he uses it to inform some friends:

"Yeah a private message always, saying that I am sick ehhe I have treatment. Some people would answer 'are you joking' ... Someone you know him for a long time and you say, 'I have [diagnosis]. They say 'are you serious'? The first time you say it, they won't believe it, when you say it for the first time."

Eric is not interested in meeting people who have the same diagnosis:

I take my [diagnosis] on my own. I don't want to talk to other people that have the same thing as I have. I spoke to people that have the same thing as I do. I understand what they are going through, but ... I don't want to talk about it. As I said, I try to live my life without being remembered that I have it. Speaking about it is a way of remembering. That is what I don't want to do, that is why I don't want to talk about it."

4. Multiple Bodies

Haraway's questions about visibility are a call for a feminist inquiry into what bodies become visible and invisible in and through technologies such as Facebook, to whom, and for what. In the four extracts I presented social media - blogs, Facebook, Upopolis,

the Game – as technologies that co-produce visible patient bodies through their affordances, designs, standards, and protocols.

The extracts show the conscious choices these four patients made when selecting a particular social media. All four patients used their Facebook account to be visible as ‘regular’ persons – Facebook enabled them to separate their social life from their patient life. Regular people have *regular bodies*, bodies that are not sick or weak or need treatment. For Stein this separation was a practical issue. He was already active on Facebook and chose to start a blog to keep track of his recovery while supporting people in a similar situation. Mari started her blog before she started on Facebook and decided to use her Facebook account to stay up to date about cultural events, friends’ activities, etc.

Both Stein and Mari made a reference on their Facebook wall to their patient blog. Amy and Eric kept a strict separation between their Facebook life and their patient life. But while Amy wrote a blog on Upopolis, the closed social network for young patients, Eric did not make himself visible as a patient. He used the online game to give himself a *strong and healthy body*. Even his parents did not inquire into his wellbeing while he was playing the game with them from his hospital bed.

4.1. HORIZONTAL VISIBILITY

Horizontal visibility, such as the profile information in a Facebook account, makes social action on the Internet possible (Stalder, 2011). The extracts make clear that patients actively use technology to manage their horizontal visibility. They make different presentations of their body visible or invisible to their online friends and other users of social media:

- *Patient bodies*

All four participants have made clear choices about if, how, where, and to whom to make their *patient bodies*, the body that is receiving treatment or that is recovering, visible online. Mari, Stein, and Amy made their patient bodies visible in social media because they are actively seeking social interaction with particular people. Mari wants to keep family and friends up-to-date about diagnosis and treatment; Stein wants to keep other patients up-to-date of his recovery; and Amy wants to communicate with kids who have a similar disease. Mari and Stein do this in a very public forum, a blog, while Amy is active in a closed social media (Upopolis), for which the only way to get an account is to be a registered young patient in a hospital in Canada. In contrast, Eric did not make his patient body visible online. Patient bodies can thus be both *public and private bodies*.

- *Healthy bodies*

Both Amy and Eric use Facebook’s public communications to be part of a group of friends with *healthy bodies* or *regular bodies*. They never mention their diagnosis, treatment or hospital stays. Being part of this group enables them to stay up to date about school and friends and their activities, while staying in the hospital.

Even though Mari and Stein did not keep the fact that they were receiving treatment or recovering from treatment from their Facebook friends, they presented only

their healthy bodies, not their patient bodies in Facebook. They used Facebook as place in which they did not have to talk about their patient bodies. On Facebook they were in touch with friends and relatives (Mari and Stein), stayed informed about cultural events (Mari), and played games (Stein).

- *Exposed bodies*

People make their patient bodies visible online, through descriptions and photos in patient blogs, discussions in patient communities, status updates about a hospital stay on Facebook, etc., in order to seek and find social interaction with peers as well as with family and friends. By seeking horizontal visibility, their bodies become also visible in other ways. A visible body is an *exposed body*, an *unprotected body* that can be used for activities that are not considered social. Exposed patient bodies can be quantified, aggregated and made commercially available by the provider to other companies. Several online patient communities are based on this model. Exposed patient bodies can become *quantifiable bodies*, they can be measured in pressure, temperatures, weight, insulin, cholesterol, medication use, side effects, etc.

It is possible, as Amy's case shows, to seek horizontal visibility without having to trade off vertical visibility. Amy has started a blog on Upopolis, which is a secure social network run by a children's foundation. Through the blog she has come into contact with some kids who have a similar diagnosis. It gives her a connection, which she doesn't have with her friends on Facebook.

- *The protected body*

While Mari and Stein make their patient bodies visible online, Eric tries to keep his patient body invisible. He is only a patient when he is receiving treatment in the hospital. When he is online, he wants to have a *normal body*, like everyone else. Both Amy and Eric use Facebook to present themselves as "normal" teenagers. Eric doesn't want to be reminded that he is sick. Mari expresses this in a different way: she is not interested in meeting patients with a similar diagnosis because she doesn't want to be "exhausted from other people's problems".

4.2. VERTICAL VISIBILITY

Patients actively use technology to manage their horizontal visibility towards other social media users. Mari, Stein, and Amy use one technology to be a patient and another to be anything but a patient. When Mari became more sick, she could not keep the two, Facebook and blog, separate and she resorted to one technology for her last messages. Eric's patient body is missing online. This is not necessarily because of privacy concerns. His way of dealing with a potentially deadly illness is to make his patient body invisible.

While the patients used social media to make certain bodies visible or invisible to particular groups of social media users, the same technologies makes all patient bodies visible to the social media providers, who can make these data accessible to other third parties. This vertical visibility is invisible to the patients. For example, all four patients have a Facebook account in which they use their real name, profile picture, school or work place. This is a requirement of Facebook and is mentioned in their terms of use.

All four also have friends-only privacy settings. Amy and Eric do not publicly discuss their diagnosis and treatment on Facebook, but they use Facebook private messaging system and private chat to organize the hospital visits of their family and friends.

By using Facebook, all patient bodies, including Amy and Eric's invisible patient bodies, are visible to Facebook the network provider. This vertical visibility is based on Facebook's records, which includes the IP addresses used to access Facebook, copies of private messages sent and received, copies of chats, etc. Facebook organizes the data it holds about a user in at least 57 categories (Europe-v-Facebook, 2012). This data is sold to third parties for targeted advertisement, research, surveillance, etc. Mari refers to this vertical visibility when she mentions that no one should use Facebook or blogs if one thinks of the potential to misuse the personal information that becomes available through these. She calls it an "existential dilemma", if you don't use it, you can't participate in the social interaction afforded by them. The same is true for Amy and Eric. Not participating in Facebook, as 'regular' teenagers, would mean *horizontal invisibility* (see boyd, 2007; Steeves, 2010). The trade-off between horizontal and vertical visibility is not transparent to social media users, making it impossible to oversee the possible consequences of vertical visibility. In the networked visibility of today, all online bodies, public and private, are visible bodies.

5. Concluding remarks

One perspective addressing Stalder's call for infrastructural projects that limit the vertical visibility of personal data is *Privacy by Design*. The basis for this concept stems from the notion of Privacy Enhancing Technologies (PETs), which was introduced in the 1990s (IPC/Ontario/Canada and Registratiekamer/Netherlands, 1995). Ontario Privacy Commissioner Ann Cavoukian (2009) has been instrumental in developing a comprehensive Privacy by Design program, consisting of seven foundational principles (ibid 2011) that target the individuals, organisations, and corporations that develop, manage, and control the technologies and structures used to collect, use, and store personal information by others, which we called vertical visibility.

The four interview extracts make clear that users are more directly concerned with, and actively involved in, the control and management of personal (health) information they willingly share with other social media users, which we called horizontal visibility. The four patients share information selectively, using particular social media technologies and their services, in order to make their multiple bodies visible or invisible. Horizontal visibility, the visibility that makes social interaction possible, thus consists of multiple modes of visibility, including invisibility (e.g. Eric). These modes also change over time, as became clear in the case of Mari, Stein, and Amy.

To support a multiple conception of horizontal visibility, the Privacy by Design approach can be paired with the notion of *visibility by design*. If horizontal visibility is a prerequisite for social interaction, visibility by design can support users in negotiating their online visibility according to their multiple personal, cultural, and gendered, privacy needs. While Privacy by Design focuses on vertical visibility, *visibility by design* is about spaces and tools that enable users to design their horizontal visibility,

the different ways in which they want to be visible or invisible to other social media users.

References

- Acquisti, A., & Gross, R. (2006). Imagined communities: Awareness, information sharing, and privacy on the Facebook. In G. Danezis & P. Golle (Eds), *Privacy Enhancing Technologies* (pp.36-58). Heidelberg: Springer Verlag.
- Altman, I. (1975). *The environment and social behavior: Privacy, personal space, territory, crowding*. Monterey, Calif.: Brooks/Cole Publ. Co.
- Barnes, S. B. (2006). A privacy paradox: Social networking in the United States. *First Monday* 11 (9). Retrieved January 25, 2012 from <http://firstmonday.org/htbin/cgiwrap/bin/ojs/index.php/fm/article/view/1394/1312>.
- Borren, M. (2008). Towards an Arendtian politics of in/visibility. *Ethical Perspectives*, 15 (2): 213-237.
- boyd, d. (2007). Why youth ♥ social network sites: The role of networked publics in teenage Social Life. In D. Buckingham (Ed), *The John D. and Catherine T. MacArthur foundation series on digital media and learning – Youth, identity, and digital media* volume (pp. 19-142). Cambridge, MA: MIT Press.
- Burgoon, J. K., Parrott, R., Le Poire, B.A., Kelley, D.L., Walther, J.B., & Perry, D. (1989). Maintaining and restoring privacy through communication in different types of relationships. *Journal of Social and Personal Relationships* 6 (2): 131-158.
- Burgoon, J. K. (1982). Privacy and communication. In M. Burgoon (Ed), *Communication Yearbook* 6 (pp. 206–249). Beverly Hills: Sage Publications Ltd.
- Casper, M. J., & Moore, L.J. (2009). *Missing bodies: The politics of visibility*. New York, NY: NYU Press.
- Cavoukian, A. (2011), *Privacy by design: The 7 foundational principles*. Retrieved June 2, 2011 from <http://www.ipc.on.ca/images/Resources/7foundationalprinciples.pdf>.
- Cavoukian, A. (2009). *Privacy by design ... take the challenge*. Retrieved June 2, 2011 from <http://www.privacybydesign.ca/content/uploads/2010/03/PrivacybyDesignBook.pdf>
- Europe-v-Facebook (2012) 'Europe-v-facebook.org'. Retrieved January 25, 2012 from http://europe-v-facebook.org/EN/Data_Pool/data_pool.html.
- Foucault, M. (1977). *Discipline and punish: The birth of a prison*. London: Penquin Group.
- Haraway, D. (1997). *Modest_Witness@Second_Millennium.FemaleMan@_Meets_Oncomouse™*. New York: Routledge.
- IPC/Ontario/Canada, & Registratiekamer/Netherlands (1995). IPC - Office of the Information and Privacy Commissioner/Ontario | Privacy-enhancing technologies: The path to anonymity (Volume I). Retrieved January 25, 2012 from <http://www.ipc.on.ca/english/Resources/Discussion-Papers/Discussion-Papers-Summary/?id=329>.
- Kim, J. H. (2008). A politics of visibility in the blogosphere: A space in-between private and public. In N. Carpentier et al (Eds), *Democracy, journalism and technology: New developments in an enlarged Europa*. Retrieved January 25, 2012 from <http://homepages.vub.ac.be/~ncarpent/suso/DTech.html>.
- Livingstone, S. (2008). Taking risky opportunities in youthful content creation: Teenagers' use of social networking sites for intimacy, privacy and self-expression. *New Media & Society* 10(3): 393-411.
- Norberg, P. A., Horne, D. R., & Horne, D. A. (2007). The privacy paradox: Personal information disclosure intentions versus behaviors. *The Journal of Consumer Affairs* 41(1): 100-126.

- Palen, L., & Dourish, P. (2003). Unpacking “privacy” for a networked world. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. CHI '03 (pp. 129–136). Ft. Lauderdale, Florida, USA.
- Petronio, S. S. (2002). *Boundaries of privacy: Dialectics of disclosure*. New York, NY: SUNY Press.
- Pols, J. (2010). Breathtaking practicalities: A politics of embodied patient positions. *Scandinavian Journal of Disability Research* 13(3): 189-206.
- Radin, T. J. (2001). The privacy paradox: E-commerce and personal Information on the Internet. *Business & Professional Ethics Journal* 20(3/4): 145-170.
- Stalder, F. (2011). Politics of networked visibility. *Acoustic Space* (10): 13-19.
- Steeves, V. (2010). *Summary of research on youth online privacy*. Ottawa: Office of the Privacy Commissioner of Canada. Retrieved January 25, 2012 from http://www.priv.gc.ca/information/pub/yp_201003_e.pdf.
- van der Velden, M., & El Emam, K. (in press). “Not all my friends need to know”: A qualitative study of teenage patients, privacy, and social media. *Journal of the American Medical Informatics Association*.