



## Dynamic of online and off-line watching in self-management programs

by Bethany Hipple Walters, Samantha A. Adams,  
and Roland Bal

### Abstract

In this paper, we explore the multiple types of online and off-line watching involved in self-management programs for people with a chronic disease through data collection in two disease management programs. This paper builds upon Mann's new work on veillance, which is defined as watching from above (surveillance), watching from below (sousveillance), watching data (dataveillance), and watching everything (uberveillance) (Mann, 2013; Mann and Ferenbok, 2013). This paper expounds upon veillance to include watching each other (coveillance), watching one's self (self-surveillance), and the umbrella concept of webveillance (watching of and on the Internet). We argue that these forms of veillance, as conducted through self-management programs, techniques, and technologies, affect the relationship between patients and clinicians, transform the allocation of medical responsibilities, alter the architecture of healthcare, and expand the places in which healthcare is performed. This has significant implications on online activities of patients and clinicians, as well as how and by whom healthcare is conducted in the doctor's office, the home, and public spaces.

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### Introduction

Healthcare is filled with watching and observation. Observation is one of the primary means of understanding a patient's symptoms and illness, tailoring treatments to patients, and comparing symptoms and signs between patients to create standardized notions of disease (Foucault, 1994). This trained and assessing form of watching is the medical gaze [[1](#)]. Foucault's notion of the medical gaze originated with the development of professional medical education, standardization of care, and teaching hospitals and other distinct medical spaces, like doctor's offices (also understood as the *clinic*). The medical gaze and the clinic have been expanding outside of these institutions, including online spaces (Patton, 2010; Petersen and Bunton, 1997; Lupton, 2013).

The medical gaze consists of multiple forms of observation and watching, better understood as veillance. Veillance is "a broad concept that includes both surveillance (oversight) and sousveillance (undersight), as well as dataveillance, uberveillance, etc." [[2](#)]. This paper builds upon Mann's work on veillance, defined as watching from above (surveillance), watching from below (sousveillance), watching data (dataveillance), and watching everything (uberveillance) (Mann, 2013; Mann and Ferenbok, 2013). This paper expounds upon veillance to include watching each other (coveillance), watching one's self (self-surveillance), and the umbrella concept of webveillance (watching of and on the Internet). By including 'etc.' into his definition, Mann (2013) leaves the term open for development and the inclusion of other types of watching and observing, such as coveillance, self-surveillance, cyberveillance, infoveillance, and webveillance. We define webveillance as the multiple forms of veillance that occur in and as a result of the use of networked computer systems. In healthcare, these networked computer systems include Web

sites, forums, smart phone and tablet apps, and/or networked electronic medical records that are viewed via the Internet.

The concept of *veillance* opens up the medical gaze to include more types of relationship hierarchies, technologies, and actors interacting and reacting to one another. The medical gaze is distributed, relational, technical, and stretched out over time. Clinicians become archeologists of clinical information on Web sites and records, in person and by proxy, uncovering and bringing to light data that may have been relevant to self-management of these and other patients.

In this paper, we explore the concept of *veillance* and the implications of *veillance* in the self-management of chronic conditions, using type 2 diabetes and eating disorders as case studies. Both conditions frequently entail changes in eating habits, significant lifestyle alterations, the obligation for patients to watch their activities and symptoms, and the collection of (bio)metric data. Both conditions require self-management outside of the clinic and interaction with multiple types of clinicians over a long period of time.

While research has been conducted on work, patient experience, and uni- or bi-directional surveillance in self-management (Sav, *et al.*, 2013; Pryce, 2000; Lorig and Holman, 2003; Walstrom, 2004), less research has been done on the broader concept of *veillance* in self-management, especially in regards to the multidirectionality and interactivity of *veillance* online and off. We explore what types of *veillance* are evident in self-management programs, techniques, and technologies. Further, in the findings and discussion sections, we analyze what these forms of *veillance* do. This analysis is an important addition to the fields of Internet studies, online healthcare, self-management, and *veillance*.

### *Self-management*

Treatment protocols for chronic disease rely heavily on patient involvement in the treatment and management of their condition through educating patients to self-manage (Bodenheimer, *et al.*, 2002). Treatment strategies include sharing and coordinating care between multiple medical professionals and using information systems to support chronic disease treatment (Wagner, *et al.*, 2001; Green, *et al.*, 2006).

Self-management efforts change the roles of patients and clinicians as well as how power moves between clinicians and patients. The clinicians provide structured support, guidance, education, oversight, and emphasis on patients' self-management responsibilities (Lake and Staiger, 2010). Clinicians coach patients to become the main care provider for their chronic disease (Holman and Lorig, 2004). Patients report back to clinicians during appointments, through entering data online in their record or on a Web site, or through sharing their self-management activities (Moser, *et al.*, 2008; Winkelman, *et al.*, 2005; Stone, *et al.*, 2003). Having and being treated for a chronic disease is work and involves emotional adjustment, organization, making decisions about care, and cooperating with providers (Lorig and Holman, 2003; Bodenheimer, *et al.*, 2002). While self-management has been shown to improve patient outcomes (Lorig and Holman, 2003), these improvements are an effort for clinicians and patients (Rogers, *et al.*, 2005; Chodosh, *et al.*, 2005).

This paper draws on qualitative data from two different disease management programs. The first case is an eating disorder treatment center near Amsterdam. At the time of data collection, the center had a four-fold disease management program that included a Web site to support and encourage (mostly) young women with eating disorders or eating problems, an online eating disorder assessment tool, a visiting nurse program, and an expert patient/support group program based in the center. The second case was a project based in practices of a large general practice (GP) group near Utrecht. The program focused on managing adult-onset diabetes through patient self-management and coordinated care between medical professionals, conducted via meetings, phone calls, and a networked electronic patient record. The program has been in existence for over 10 years, though it has further developed through recent funding. Patient self-management activities occurred through coordination of clinicians and through direct training of patients.



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## Methods

We conducted this research as part of a larger study of disease management programs in the Netherlands, which was funded by the Netherlands Organization for Health Research and Development (*Nederlandse Organisatie voor Gezondheidsonderzoek en Zorginnovatie (ZonMw)*). The Ethics Board of the Erasmus University approved the data collection of the overarching study. We collected the data through interviews, observations, and Web sites from the two cases analyzed.

We conducted 32 interviews in total at the two case sites. The interviews focused on the development and implementation of disease management programs, with special emphasis placed on self-management. The interviews were recorded when possible; due to equipment failure, one interview was not recorded. Twenty-five semi-structured interviews were conducted with the project leaders, medical professionals, and communication specialists at the sites. Seven

interviews were conducted with patients in the diabetes project and focused on the patients' experiences with diabetes and treatment. Data has been presented anonymously.

Data was collected from the eating disorder treatment center's Web site, primarily but not solely from the 'experience stories' portion of the Web site. The 'experience stories' are narratives written by young women about their eating disorder and treatment. Other data was collected from the privacy statement pages of the site, as well as from advice articles written by volunteers and/or staff of the Web site. All data was collected from pages available without a log-in.

Two half-days of observations of nurse specialist and nutritionist visits were conducted in the diabetes case. One morning of observation of the two-morning diabetes education course was also conducted. One GP cooperative meeting was observed, and two meetings at the eating disorder center were observed.

We analyzed the collected data inductively through close readings of the raw data and through coding based on themes found in the data (Thomas, 2003). In specific, the first author read the transcripts, observation notes, and data collected online; she then coded the data into themes that arose from the close reading by copying sections into separate documents, based on the themes uncovered. The second and third authors approved the coded quotes selected for this article. The first author translated the quotes from Dutch, and a native Dutch speaker validated them. When possible, interviewees reviewed and approved the quotes for use in this paper. Our chosen method of inductive analysis provided the opportunity to map the themes back to literature on disease management, veillance, and self-management (Creswell, 2013).



## Findings

Our data shows how the forms of veillance interact in and outside of the clinic, in the lives of patients, and in the delivery of healthcare. This proliferation and interaction shows that there has been a change "from understanding society as strictly an oversight system [to] one that has potential to be multi-channeled" [3]. In self-management programs, this multi-channeled veillance system involved multiple actors over time, with the circumstances of veillance altering as the programs, technologies, and actors changed.

### *Training, coaching, and accountability*

Self-management relied, as noted by Tattersall, on a "sea change in attitudes among patients, and more importantly, healthcare professionals" [4]. In the diabetes program, the first step towards changing the attitudes of healthcare professionals was education. Clinicians were trained through meetings and trainings to deliver self-management support and education to patients. Education for clinicians was often paired with data veilled from the networked electronic medical record. In fact, the data from the networked electronic medical record influenced the type of training offered. For example, when webveillance of the aggregated data from records revealed a significant number of Muslims, an instructor was brought in train clinicians to address diabetes, Ramadan, and self-management.

For patients, too, one of the first steps in conducting self-management was being trained to conduct self-surveillance. Self-surveillance is "usually understood as the attention one pays to one's behavior when facing the actuality or virtuality of an immediate or mediated observation by others whose opinion he or she deems as relevant — usually, observers of the same or superior social position" [5]. The behaviors were observed by clinicians via the data that the patients collected on their chronic condition (food diaries, glucose readings, etc) and through the patients' online and off-line reports of their lives with a chronic condition. Patients were trained by clinicians to conduct standardized self-surveillance using tools and approved methods. The resultant standardized data from multiple self-managing patients allowed broader dataveillance of the record across practices.

The trained skill of self-surveillance came, in the diabetes project, via one-on-one meetings between clinicians and patients and/or through voluntary group classes on diabetes self-management.

*Through two mornings (in group classes), patients are educated about diabetes, the risks, nutrition, medication. The principle is that you don't impose anything [on the patients] but if you make people responsible for their illness through self-management, it works better. [Interview with GP; diabetes project]*

Responsibility was another 'skill' that patients learned. Responsibility was a very specific form: compliance with clinicians' recommendations, self-managing according to standard means, being and staying knowledgeable, using tools, knowing and reporting health metrics, being available for veillance. Responsibility was seen as the core of self-management and, as a result, self-surveillance. The information collected through self-surveillance represented the experience of a

disease in tabulated numbers, written accounts of foods eaten, and changes in symptoms. This information provided clinicians the opportunity to tailor care to the patient and the disease that the data represented, to add the data to a larger repository of data on diabetes, and to understand if their training of patients in self-management and self-surveillance had been effective for the needs of the patient and of the clinic.

There were a variety of reasons for clinicians to believe that the training and education in self-management had been ineffective.

*They [patients] know so little, they know so little ... Why is that? I don't know. They come to me, and most people know so little. And then I think, 'you've been to the doctor, you've been to the chronic care provider, some have been to the diabetes nurse ...' There is so little retention of what everyone has said. [Interview with nutritionist; diabetes project]*

The causes for the lack of retention weren't necessarily clear to clinicians, as it was not always in the record (available for dataveillance) or made apparent in the visit (available for surveillance). Rather, the networked electronic medical record showed that the patients had encountered many clinician educators, and had, in principle, many opportunities to learn how to self-manage. Surveillance during the visit (of patients' lack of retention) and veillance of the online record (of the education that patients had been given) created a problem that clinicians would continue to try to solve by offering more education and support.

In line with the work of Henwood, *et al.* (2003), some patients in the diabetes project were (at least at some points during the course of their illnesses) reluctant to accept responsibility for the management of their chronic condition.

*And also until now I have more or less waited till somebody said you have to do this or this. Because I missed two appointments with the chronic disease specialist assistant, very strange because normally I am very careful with appointments. I missed it twice, because simply either I didn't want to do it, internal resistance or at least it didn't live in my awareness that it was important. [Interview with patient D; diabetes project]*

The patient could not give a definitive answer for his/her own lack of participation in treatment, though self-surveillance revealed possibilities: the patient was not used to being responsible for his/her own illness management, the patient wasn't aware that the appointments were important, or he/she faced internal resistance. In short, the patient was not ready to 'do' diabetes as recommended through the self-management education by clinicians. As Mol noted in her work on diabetes, bodies (and chronic diseases) are something that people both *do* and *have* (Mol and Law, 2004). Doing diabetes, especially doing self-managed diabetes, meant the physical and mental work of living with a chronic condition. Doing self-managed diabetes required a change that the patient was not ready to make at the moment. Missing appointments and the associated missing data was a source of data for dataveillance aspects of webveillance. Missing data had the potential to shape care.

While numeric data played an important role in the self-management and veillance of diabetes, numbers alone did not always drive the visits. During an observation of a clinical visit between a diabetic specialist nurse and a patient, the patient's self-collected data revealed unusual and unhealthy trends in his/her blood glucose. The nurse, upon learning of the changes, asked why; the patient had recently quit smoking after a decades' long habit, and the change was reflected in the biometric data. Dataveillance of biometrics alone would have shown 'unhealthy' data without revealing the rationale. Once the rationale was found, the conversation turned to congratulations and methods of quitting smoking; there was no change in the course of treatment. The numbers were a catalyst for further discussion and surveillance during the visit.

The eating disorder project approached self-management in similar ways: through training, through shifting responsibility (and power) to patients, through working with patients outside of the clinical setting. In the eating disorder project, it is clear that before training patients, clinicians first had to surveill the patients to understand how the chronic condition might impact patients' abilities to self-manage and conduct self-surveillance.

*Oh yes. So now, during the intake phase, we try to work with the client to have them get more control over their own treatment plans. And the aim is that a kind of co-production will occur between clients and professionals. That's difficult ... Because the clients are so passive and they sometimes do not know. And their weights are too low, so sometimes they cannot think clearly about what they want or how it looks or what really is their request for help. They often do not know. So you have to help them, you have to teach them to figure out, what can we (at the clinic) really do for you? [Interview with first project manager; eating disorder center]*

According to those at the center, the patients' disease limited their ability to learn about self-management and conduct self-surveillance. The center's desire for patients to have more control over their treatment had to be balanced with care for the critical aspects of their conditions. Similar to findings by Broer, *et al.* (2010), the clinicians first removed constraints to autonomy and responsibility (in this case, constraints caused by the condition, as patients with severe eating disorders were not considered rational due to low weight as a result of their disease) and worked to learn patients' preferences. To do this, the treatment center provided an 'overdose' of treatment.

*Rather, what we do now, the clients come to the clinic and they get an overdose of therapy. In particular, it's the basic groups that will be important. Those are important. There you [the patient] work on your eating disorder and clarify your request for help. Then you get a program comprised of modules, made up of the therapies you are going to follow.* [Interview with first project manager; eating disorder center]

This overdose of treatment had multiple functions, some of which were unspoken: to improve the physical condition of the patients and improve their cognitive processes by eating, to show the patients that they are supported in their treatment (what can we really do for you?), to observe the patients as they were being treated, to balance the patients' control over their treatment with the limitations imposed by their physical and mental conditions, and to show the patients what treatments were available. This overdose of treatments created the opportunity for surveillance, watching the treatments and clinicians from below in order to see what treatments would work best for them, and an opportunity for self-surveillance as they were encouraged to think about and report back on which of the offered treatments would be most effective for them.

Self-management training and coaching was also conducted via the center's Web site for young women with eating problems/disorders, who were not necessarily patients at the center. Interacting with the Web site users in a standard clinical setting was not possible; the Web site and wherever it was accessed were the locations of treatment. Self-management and surveillance were facilitated by technology.

*If I look at what our girls on [the Web site] do is that they take some here, take some there. Why not try to provide them with what I would call more self-management tools, but what you could also construe as smaller, individualized therapy modules or intervention or whatever ... Just offer a food diary or just offer ... a cognitive tool in which you can analyze your thoughts and restructure ... Sort of take traditional treatment but cut it up into smaller components, offer those as self-management tools.* [Interview with project leader; eating disorder center]

The Webmaster and the project leader conducted webveillance by reviewing Google Analytics reports and looking at the postings of young women. The surveillance was unseen — not quite hidden, as the Web site did state that it would collect data for quality improvement — but not directly observable by the young women; they did not know which of their postings would be read by the project leader or which of their page views would shape the project leader and Webmaster as they changed the site. The surveillance was unobtrusive, but influential.

#### *Observing and monitoring*

While much of the observation by clinicians of the patients' self-management was done by proxy or of the information in the record, some of the surveillance was quite direct, quite visible, and quite personal.

*One of my patients is now in the hospital due to underweight. This is primarily a somatic indication. And three times in the week, I sit with her for one of her meals ... They say that the first bite is hardest, so I'm a bit strict there.* [Interview with nurse; eating disorder center]

The young woman with an eating disorder was not able to be responsible the management of for her own condition; she was hospitalized for very low weight, which (as an earlier quote pointed out) was understood to impact cognitive capabilities. The nurse and patient sitting together was 'surveillance made visible'. This direct surveillance was part of the treatment, much as other forms of surveillance are components of treatment. In this instance, the nurse watched her patient eat and, while watching, modeled mealtime behavior. This surveillance was intended to be seen and internalized by the patient, who would then, the nurse hoped, be able to eat without direct surveillance by nurses or family members.

Sometimes surveillance was about what should not be seen or recorded by whom. For young women with an eating disorder, eating and the physical impacts of eating, especially weight gain

reflected in the numbers on a scale, could be distressing. However, this number was seen as sometimes necessary for self-management.

*Blind weighing is a good option to break your relationship with the scale or not to restart an old one. [Someone else] can look and tell you only when there are notable increases or decreases. This can be done for example by standing backwards on a scale. [Article on eating disorder support Web site]*

Advice on the eating disorder support Web site suggested that the users seek out assistance in self-managing. This assistance would come in the form of surveillance and dataveillance by a trusted outsider, who would not reveal the collected data, merely trends; no joint dataveillance would be conducted. Here, patients were hoped to self-manage the limitations that their eating disorder placed on their behavior and be disciplined not to look and not to conduct behavior that may have contributed to their eating disorder.

In the diabetes program, what was seen and unseen was different. It focused on what was intentionally not surveilled by clinicians and not documented in the record.

*I put the weight when I weighed [patients]. You have to put the weight in the record; it's mandatory. Sometimes I do not weigh people because I don't think weight's important. Then I just put the old weight that was already there into [the record]. I occasionally look at the medical history and sometimes not; it depends whether I think it's important. And from my plan, I write my notes about what I think is important for GPs and practice nurses know. What have I discovered? Yeah, that's actually the conclusion. [Interview with nutritionist; diabetes program]*

Using a technology for veillance (here, a scale) was seen as unnecessary for treatment by the nutritionist. Rather, the clinician focused on what she thought was important for the patient and for other clinicians who might view the data added to the record. Veillance was, in some ways, built (or not) through a series of choices that the clinician made. This was also shown in the quote above: what was not seen and not recorded can be just as important to self-management programs as what was seen and was recorded. This is a contrast to the more Panoptic view of watching put forth by Foucault and others, in which those who watched are potentially always watched from above (Simon, 2005; Petersen and Bunton, 1997; Foucault, 1995). Not watching was a deliberate treatment choice based on the importance of the data, as determined by the clinicians and/or patients.

How data was shared and not shared played an important role in self-management. Patients shared the veillance of data through self-surveillance and collecting their own data, through sharing this data with clinicians, and through looking, with their clinicians, at their collected data in the networked electronic medical record.

*I'll let patients look at the results on the screen, for example lab results. [The electronic medical record] will show a graph. For example, when glucose readings are taken, then there will be a very nice graph. So then I show the patient. I turn my screen and I show patients, 'look, this happens and it's good or it's bad'. I'll do that. Yes, yes. It is kind of educational, increasing the self-awareness of the patient. I always report what is Gly-hb. And therefore they often look at me in confusion and I spell it out again. Then I think, you heard about it sometime back, that Gly-hb is important, you should know this term, you know the term glucose, you should know the term carbohydrates. So I try to not talk in sugars or bad sugar, but when I talk, I say diabetes, carbohydrates, glucose. They just need to know these things to increase their awareness, like what are we talking about now. I think that is actually very important. [Interview with nutritionist; diabetes program]*

The clinician created the opportunity for joint dataveillance of the networked electronic medical record by turning the screen to share data. This dataveillance done together was an opportunity to bring the patient into the medically dominant care process through education on the correct terms used in diabetes care, through the emphasis on what the clinician considered important, and through increasing the patient's self-awareness. This veillance was collective and both online and in-person, but done on the terms of the clinician with the goal of educating and improving internalization of self-management principles.

#### Online

While both programs used Web-based platforms to support self-management, they did so in different ways. The eating disorder center focused more on outreach to young women with their

Web-based efforts, including via a Web site for those with eating disorders. Participating on the site was voluntary. The Web site allowed clinicians to come to the patients to provide treatment, support, and self-management.

*And that is why e-health is so important to us. You are immediately in someone's living room and that is why there is less of a barrier for him/herself. [Interview with second project manager; eating disorder project]*

Those who used the site may have had no other treatment for their eating disorder, becoming, through their use of the site and the veillance that the site facilitated, online-only patients. As the site was open to the general public, the use of the Web site expanded the clinic and included the online-only patients in the medical gaze. The site served as an online personal health record for the young women, open to the review of themselves and/or their peers. The Web site became an online communal medical record which was open to the webveillance of others, including clinicians.

As archeologists of clinical information, clinicians and Webmasters conducted veillance on more than the words and pictures posted online, but also of the data that the Web site kept. This was, as others have noted, a form of governmentality, which "operates on particular groups, using the gathered information with statistical analysis, financial reports and population registers" (Rajagopal, 2014). This governmentality can be seen through the redaction of elicited information, such as names of diet drugs, body weights, and pro-eating disorder messages; such information was removed and repeat offenders were blocked by IP address and/or username. This webveillance, including cyberveillance, shaped care.

In the diabetes project, Internet-based efforts included a Web site, a monitored forum for clinicians, and a networked electronic medical record. The site was for the entire GP cooperative, with a special section about the diabetes program. While the Web site had self-management information, there was little data to suggest that patients or clinicians used the site frequently. Rather, (some) patients went to other online and off-line locations for information.

*Of course I already know a lot already, because I've also searched a lot on the Internet and also received information from the doctor and I was just curious what ... if they still might add something. Any information you can get is important. [Interview with patient C; diabetes project]*

*What I did notice is the dietician is very nice, but she does not have a very good feel for teaching ... I went to her before as a dietician and I quit, because I just couldn't get the bigger picture. I went to the Internet and I got everything I wanted in one package. And what I need more with a diet is the motivation to do it. And for that I have to have a clear mental picture and I think this is giving me that ... Yeah I think I went to a hospital in xx. There they had a pamphlet; they had everything I needed to know ... And then, suddenly, all the pieces came together. [Interview with patient D; diabetes project]*

Sousveillance changed how patient D collected information on his/her chronic condition. The Internet provided educational materials and a work-around for poor patient-clinician match, as well as the opportunity for another form of veillance. While the clinicians at the diabetes program did not know what the patient had downloaded, the hospital from which the patient downloaded the information did — through the webveillance of their site [6]. The sousveillance of the clinician had a ripple effect in how this patient (and possibly future) patients inside and outside of the diabetes program were educated to self-manage.

Other online tools included the networked record. The record contained various forms of information and biometric data, allowing clinicians to tailor advice, prescriptions, and education based on historical trends for patients.

*Yeah, so in principle, I can (write) in the whole file and in the diabetic file. And I can open up the diabetes file for other clinicians: the optometrist, the nutritionist, the podiatrist, the physical therapist, the diabetic specialist nurse ... And that is pretty easy; it gives patients a bit of security that their private information (and) their privacy is well respected. Otherwise anyone anywhere can look in. [Interview with practice nurse; diabetes project]*

The staff at the GP's offices had the ability to limit veillance on the record. The record was a site of dataveillance (when the clinicians looked at the records through the local program in the office) and of webveillance (when the clinicians used the online interface to view the records). Reduced access limited the dataveillance and webveillance that were possible. This reduction possibly shaped self-management education and support, as not all clinicians had a complete

overview of a particular patient's health record. The clinicians at the GP's office valued patient privacy over having all data available to veillance by all clinicians involved in the care for a patient's chronic condition; data open to veillance was seen as a tool to be used by certain people in defined circumstances.

Patients in the diabetes program had the option of viewing parts of the networked electronic medical record through a patient portal. The majority of patients had not chosen to access their records at home. While it was frustrating for clinicians to see the lack of participation, it was not unexpected.

*But we must realize that only a certain percentage of the diabetes patients will really work with that (online system). But that's what we also said, that's for now because not everybody works with a computer yet. And not everybody is well-equipped enough to use it. [Interview with first project leader; diabetes project]*

By electing not to use the portal, the patients were electing not to interact with their clinicians in the record system, not to conduct webveillance on their own medical record, not to add data that would be webveilled by clinicians, and not to take part in this aspect of self-management. Opting out of the patient portal had the potential to impact care at the group level (as there was less data from the patient portals available for reports on care over the project), at the clinician level (as clinicians had less information available about the patient), and at the patient level (as patients had one less way of interacting with clinicians, relying instead on calling clinicians and visiting the clinic).

However, opting not to use the patient portal did not mean that patients did not use other electronic methods, such as insulin pumps and glucose meters with data collection capacities, to collect and record their data.

*Well you have all the tools, I mean you can even simply transfer all your readings to your computer, you get nice graphs of how it is going, and it helps that you have a visual. I think that started when you got the USB stick. Because when you see it on a graph, visually, yeah that is a lot more confrontational than just a list of numbers. [Interview with patient D; diabetes program]*

Technology altered how the patient did diabetes. The monitor stored the collected data and had the option of dataveillance via graphs on a computer, rather than in a notebook, on the screen of the clinician, or in the patient portal of the networked electronic medical record. The ways in which he/she did diabetes altered the veillance structure; the patient limited the amount of webveillance that could happen by not adding data to the record, the patient limited the surveillance possible by skipping appointments, the patient chose technological means of self-surveillance that provided graphs similar to those that clinicians provide, the patient came to group trainings, which allowed for surveillance and veillance in a group setting. Doing diabetes did not mean that he/she followed the self-management instructions of his/her clinicians exactly but created a personalized, technological way of doing diabetes and conducting self-surveillance.

The technological tools associated with self-management changed the locations of self-management and of veillance, blurring the boundaries of the clinic. Through the use of these technologies, we can see the mutual relationship between veillance and self-management; the ways in which these technologies were used/not used impacted the veillance possible.



## Discussion

Veillance and self-management were intrinsically linked through the interactions of patients, clinicians, project leaders, and technological systems such as glucose meters, Web sites, and networked electronic medical records. This linkage impacted what both veillance and self-management did in patients' lives, clinical practice, and project management.

### *Veillance as a clinical tool*

As a clinical tool, veillance worked at different levels of care through different technologies. This included how veillance impacted and was impacted by how patients self-managed, how clinicians treated patients at the individual level, the group level, and at the aggregated level, how care was managed, and how chronic disease programs were funded and studied.

One of the key features of self-management education was training patients to become more responsible for their own chronic condition; this included education on how, when, and what to self-surveil. Responsibility was not handed over without restrictions but was transitioned over gradually through education sessions with multiple clinicians, through group classes, through exams, and/or through Web sites. Supervision was ever-present in the form of patient self-surveillance and the possibility of clinician surveillance and dataveillance; clinicians and patients



(as part of the same self-management team) controlled the body and the chronic disease. Self-management was primarily defined and steered by the clinicians, who taught patients to be responsible for their condition and watch themselves in various ways as if they were clinicians themselves. As others have shown, the emphasis on learning and expertise for patients can focus on the biomedical model of care to the detriment of other understandings and ways of doing and having a chronic condition (Fox, *et al.*, 2005).

Clinicians, patients, and project leaders were disciplined into internalizing the gaze. This disciplining occurred through education, through the ever-present potential of supervision, through steering by others, and through controlling the body (Foucault, 1995). Without the expectation of internalized discipline, self-management (and veillance associated with self-management) would not have been possible. Discipline expanded the realm of the clinic outside of the doctor's office or hospital.

### *Case comparison*

The two programs provided an interesting lens through which to understand how the types of veillance interacted and impacted patients' lives, clinicians' actions, and the delivery of healthcare. The two cases had different patient populations. The diabetes population was significantly older than those being treated for an eating disorder; many of the young women at the eating disorder site were online only patients or were in-patient, in contrast to the diabetes patients who lived at home; the patients with diabetes were thought to be less computer literate than the average population. The differences in the populations affected how and what types of veillance occurred. As the eating disorder center had many more patients online, webveillance played a larger role in the delivery of care than in the diabetes program. Through webveillance, the clinicians and Web site managers observed what the young women did and tailored offerings accordingly. As the patients in the diabetes program saw many clinicians at multiple locations over a longer period of time than those were seen in the eating disorder program, dataveillance of data in the networked electronic medical record played a role in tailoring care to the patient and to groups of patients as a whole. The types of veillance used and the self-management techniques promoted were affected by the types of patients seen.

In both sites, clinicians focused on shifting responsibility for the chronic condition to patients, on self-surveillance, on veilling patients at the individual and group level, on collecting and analyzing data to better tailor care. Patients watched the actions of clinicians (either directly or by coveilling the experiences of others) and changed their behavior accordingly. Neither patient group had full responsibility over their disease, despite the efforts to shift responsibility towards them: the young women with eating disorders were seen as too physically weak to have full responsibility for their eating disorders while those with diabetes were seen as too passive and too computer-illiterate to have full responsibility for their records, their diseases, and their bodies.

### *The prevalence of webveillance*

While surveillance and dataveillance on the Internet have been well-researched (Ball, *et al.*, 2012), veillance online is much broader. Webveillance is an umbrella term for online watching and includes multiple types of veillance, such as infoveillance, cyberveillance, dataveillance, surveillance, coveillance, and sousveillance. These aspects of veillance may be conducted individually but are more likely to be conducted collectively, with clinicians (or patients or Web site users or project leaders) looking at multiple sources of information at the same time for slightly different, but interacting reasons. As Rich and Miah (2006) noted, while early concepts of the Internet saw it as a non-corporeal space, it is increasingly seen as a "medicalized cyberspace within which the virtual and corporeal are enmeshed" [7]. The self-management programs revealed this enmeshment; the data doubles of the body (in the networked electronic record, on a forum, on the eating disorder support site) and the bodies themselves impacted and were impacted by the self-management programs. The data doubles created a different patient altogether, one that existed in the records kept by the clinic, in the data kept (or not) by patients which was entered into the records, and on the Web site. These data doubles contained information about patients' chronic condition that was disembodied, done in the data rather than in the bodies and lives of those with the conditions. These data double patients were ill in their data only, managed in their data only, and their data, though incomplete, was available to be veilled separate from their bodies.

The distinction between online and off-line blurred in care and in veillance. As seen in the eating disorder Web site, care (especially self-managed care) was increasingly provided online. The veillance followed the care, as the clinicians watched the patients and the patients watched the clinicians both online and off, noting their experiences of offline care in an online environment. Web-based information was only a part of the information taken into account when healthcare decisions were made, including those related to self-management. Webveillance also showed how the boundaries of the clinic and of care blurred. In the diabetes project, clinicians were no longer limited to viewing the record in the office (or bringing records home), while patients were given the opportunity to view the record on their own. As noted by Marwick (2012), "technology blurs the boundaries between formerly strict categories", such as clinical spaces and non-clinical spaces, clinician and patient, online and off-line [8]. As we show in the following section, non-clinical spaces became spaces in which healthcare and veillance were conducted.

### *Veillance and the clinic*

In both projects, the power and responsibilities for caring for chronic conditions were shared between clinicians, patients, and sometimes patients' families, with some researchers claiming that sharing responsibilities embodies effective chronic illness management (Thille and Russell, 2010). Patients managed their chronic condition outside of the doctor's office and reported data back to the clinic for veillance. This reported data changed the ways that care was provided during the visit, during future visits, and, potentially, outside of the exam room by the patient conducting self-management activities.

The expansion of the clinic and associated veillance could be seen in the growth of Web-based self-management activities. For those visiting the Web site of the eating disorder treatment center, there may have been no physical clinic, yet self-management occurred, assisted by the counseling sessions on the site, by the peer-to-peer relationships formed on the site, by the tools provided for clinicians, and the ability to post for help. Without veillance, this expansion would not have been possible. Users of the site watched themselves (self-surveillance), their peers (coveillance), and the clinicians (sousveillance) to self-manage, while the clinicians and Webmasters on the site watched what the young women wanted in terms of self-management (surveillance, dataveillance), monitored the postings on the site (surveillance), and responded to the needs of the online community. At the diabetes site, the expansion of the clinic via online activities can be seen in the networked electronic medical record, the Web site for patients, and the forum for clinicians. Patients, too, could access their own data and records via the patient portal of the networked electronic medical record. This webveillance of their health information allowed them, in principle, to alter their self-management activities conducted outside of the clinic based on their medical history, and to observe the digital world of their clinicians. Clinicians had opportunities to interact outside of the clinic. Clinicians were able to interact (and coveill) each other through the monitored forum. The clinic existed online, accessed in the home, offices, and Internet-friendly spaces by patients, clinicians, Webmasters, and project leader. No matter where the clinic was virtually visited and where self-management was conducted, it was a site of veillance. While veillance could not capture all of the ways in which veillance was done by the activities, thoughts, and data related to a chronic condition, veillance was (potentially) constant in the lives of patients, clinicians, and project leaders.


#### *Veillance of and by others*

While this paper has focused on the veillance conducted by project leaders, clinicians, patients, and Web site users, it would be shortsighted to assume that these are the only actors conducting veillance on and in the self-management programs. In order to study the programs and ultimately write this paper, we (and the other researchers on the team) conducted veillance on the programs: surveillance when we observed meetings and clinical visits, webveillance as we explored the eating disorder support site, dataveillance as we reviewed survey and economic data about the programs. Researchers were not the only external actors conducting veillance on the programs; others included, but were not limited to, health insurance companies, the ministry of health, and technical consultants. You, as a reader of this paper, are also conducting veillance by observing the interpretation of the self-management programs, reading the quotes and agreeing (or disagreeing) with the analysis. Your reading, too, has power; you have the power to cite the article and to recommend (or not) the paper to others.



## **Conclusion**

In the self-management programs, watching was not limited to one particular time or to those listed in this paper, but grew and continues to grow over time, as the self-management programs continue, as the articles about the programs get read, and as the funded sites grown and seek more funding, writing about their programs in funding proposals. While veillance is thus a layered concept, this paper has explored some of the specific effects that different types of veillance produce in clinical settings, producing specific types of patients and clinicians as well the relation between them.

Multiple forms of online and off-line veillance were apparent in the self-management programs. These forms of veillance were multifaceted, architectural and built into the structure of the self-management programs, multidirectional, and conducted via multiple technologies and tools. While, in principle, the types of veillance are easily distinguished and distinct, the types of veillance blurred, in practice, for those who were using them. Those who were watching may not have known what kind of veillance they were performing at any one given time and were, in all likelihood, conducting multiple forms of watching simultaneously. The various types of veillance were impacted by and impacted how self-management was conducted. This could be seen, for example, in how what the girls used on the eating disorder Web site shaped the site, as learned through webveillance by the Webmaster and project leader, in how the clinicians at the diabetes shaped their message to the individual, based on the information learned through the veillance of the record and through the direct surveillance of the patient in front of them in the exam room. Through our exploration of self-management programs, it is possible to see how veillance was a powerful force in care delivery in the clinic and beyond. 

## About the authors

**Bethany Hipple Walters** completed her Ph.D. in 2015 at the Institute of Health Policy & Management at Erasmus University in Rotterdam, the Netherlands.

Direct comments to: walters [at] bmg [dot] eur [dot] nl

**Samantha A. Adams** is Assistant Professor at the Tilburg Institute for Law, Technology, and Society at Tilburg University in the Netherlands.

E-mail: S [dot] A [dot] Adams [at] uvt [dot] nl

**Roland Bal** is Chair of the Health Care Governance group and Director of Education at the Institute of Health Policy and Management at Erasmus University in Rotterdam.

E-mail: bal[at] bmg [dot] eur [dot] nl

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## Notes

[1.](#) Foucault, 1994, p. 33.

[2.](#) Mann, 2013, p. 1.

[3.](#) Mann and Ferenbok, 2013, p. 32.

[4.](#) Tattersall, 2002, p. 229.

[5.](#) Vaz and Bruno, 2003, p. 273.

[6.](#) The patient gave the name of the hospital, which has been removed for anonymity. However, the disclaimer page of the hospital's Web site stated that the site uses Google Analytics to understand how the site is used.

[7.](#) Rich and Miah, 2006, p. 1.

[8.](#) Marwick, 2012, p. 386.

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