Article

Observing the Others, Watching Over Oneself:

themes of medical surveillance in society

Susanne Bauer

Medical Museion, University of Copenhagen, Denmark. mailto: sbau@sund.ku.dk

Jan Eric Olsén

Medical Museion, University of Copenhagen, Denmark. mailto: jeon@sund.ku.dk

Abstract

This article explores two instances of medical surveillance that illustrate post-panoptic views of the body in biomedicine, from the patient to the population. Techniques of surveillance and monitoring are part of medical diagnostics, epidemiological studies, aetiologic research, health care management; they also co-shape individual engagements with illness. In medicine, surveillance data come as digital anatomies for educational purposes and clinical diagnostics that subject the body to imaging techniques, but also as databases of patient collectives that are established in large-scale, at times nationwide, epidemiological studies. We will show that techniques of medical surveillance now include more bottom-up and less-centralized modes as well: with web 2.0 applications, one encounters endoscopic clips uploaded and made public on the internet and tools to navigate through patterns of sickness in urban space. Surveillance techniques directed at individual patients and at population health reconfigure the constellation of the body, space and the gaze into a post-panoptic distributed mode.

Introduction

This paper is an attempt to explore the reconfiguration of space, body and gaze in recent biomedicine. The constellations of the body and the medical gaze and their location in space were closely intertwined with specific epistemologies of medical science and practice at different historical periods. Michel Foucault localized the birth of the clinic in the spatialization of disease and bodies, which took place with the structuring of hospitals according to nosological categories (Foucault 1963). Inspired by Foucault's analyses of the clinical space, David Armstrong coined the term 'surveillance medicine' as 'a significant alternative model to hospital medicine and pathology, which emerged during the 20th century around the observation of seemingly healthy populations' (Armstrong 1995: 393). Medical thinking in terms of surveillance embraces probabilistic rationality and prediction, which have continuously proliferated in medical research and in public health, for instance in early diagnostics or decision-making in the clinic and in preventive medicine. Drawing on examples from clinical diagnostics on the one hand and population health surveillance on the other hand, we explore recent reconfigurations of the clinical gaze in western biomedicine. In these recent forms of diagnostic monitoring an augmented space of digital visualization and statistical data, an abundance of numbers and images is created and the clinical gaze is being delocalized. In large-scale epidemiological studies, health data from whole populations are used for risk calculations that inform policy making. Both the body and society are governed by data analyses and numerical profiling; interventions are made in a rationality of prevention at ever earlier stages. This paper thus refers to developments that take place within western biomedicine and are products of the latter; in a

Bauer, Susanne and Olsén, Jan Eric. 2009. Observing the Others, Watching Over Oneself: Themes of Medical Surveillance in Society. *Surveillance & Society* 6(2): 116-127.

<http://www.surveillance-and-society.org> | ISSN: 1477-7487

© The author(s), 2009. | Licensed to the Surveillance Studies Network under a [Creative Commons Attribution Non-Commercial No Derivatives](https://creativecommons.org/licenses/by-nc-nd/4.0/) license.

global perspective, however, there remains a digital divide in terms of access and availability of information technologies.

Our themes – monitoring the patient-body and population surveillance – can be read as representing both poles of biopower, in the sense the term has been introduced by Foucault: the gaze is directed both upon the individual body and the self as well as upon the collective ‘population body’. Taking up these two poles of biopower, we explore the digitized and transparent individual patient body of the clinic on the one hand and the epidemiological databases originating through public health surveillance practices on a population scale on the other hand.

In doing so, we pay particular attention to the more distributed forms of contemporary surveillance, which go beyond the classic spatialization of the body in the clinic and the accounts of Jeremy Bentham’s panopticon (Foucault 1975). Drawing on surveillance studies, we take inspiration in the concept of panopticism and synopticism, as proposed by Thomas Mathieson (1997). In other words, we are asking about who is observing and who is being watched. What constellations between individuals, bodies and data do we encounter in the worlds of biomedicine and epidemiology? Which specific modes of knowing do such digital assemblages bring about? What is the location of the body and knowledge on the body – is it still in the macroanatomic body or rather on the hard drive or in population databases? How do imaging and visualization techniques mediate medical procedures, clinical and political decision-making? What kinds of body and control practices do we face with the data avalanches of imaging techniques and databasing in the health sector?

In exploring these questions, we will examine selected biomedical sites and contexts in which surveillance is at work – often as taken-for granted and widely accepted if not desired practice. By exploring the effects of surveillance from perspectives situated in the cultural studies of medicine, this article attempts to expose the digital reconfiguration of the body as object of medical monitoring and intervention.

Reconfiguring the clinical gaze

In recent medicine, the relation between space, body and gaze, which played such an essential role for the formation of the clinic, has been reconfigured to a significant degree. This could partly be explained as an effect of the far-reaching molecularization of the biomedical body. Genomics and proteomics research has geared medical attention away from the macro-anatomical body towards a micro, sub-optical, yet at the same time global political level (Thacker 2005). The so-called -omics revolution has yielded new forms of medical monitoring which defy the spatial-corporeal configuration of the clinic. This does not imply however, that the clinical gaze, so notoriously described by Foucault, no longer operates on a macro-corporeal level. It still does, albeit not as coherently tied to a face-to-face setting as before. Changes in diagnostic techniques, medical practice, and cultural norms, have detached gaze and body from one another and redirected the attention of the former away from the latter.

If by ‘tied to the body’ we mean the specific ways in which medical observations are carried out, it is quite evident that the clinical spatiality, underpinning the act of looking, no longer builds on the physical contact between physician and patient (Weghorst *et al.* 1996). The scopic regime of nineteenth-century medicine was largely structured around the optical extension of visual examination. Through manual instruments such as endoscopes, ophthalmoscopes, laryngoscopes, cytosopes and speculums, the inner cavities of the body were subjected to clinical scrutiny. While these techniques of medical inspection, depended fully on the proximal relation between observer and observed, visualizations of the body today build on the distanced and mediated viewing of electronic images. This disintegration of the spatial unity in which bodies and gazes were once inscribed, has not only had considerable implications for diagnostic procedures. It has also had bearing on the means through which patients are rendered

observable in the name of health. In other words, it entails a change in the structure of the panopticon and a rethinking of the mechanisms of medical surveillance.

The impact of computing and electronic networks on contemporary medicine is immense to say the least. Its influence on the issue of medical surveillance or clinical monitoring is likewise profound. In fact, it is so profound, that it constitutes a crucial element of the disintegration of the clinical gaze described above. In order to better grasp the reconfiguration of clinical observation, we will look more closely at two aspects linked to the digitization and mediation of medicine today. The first aspect relates to what has been described as a dissemination of the panoptic model of asserting power through technologies of transparency. Rather than maintaining control over the subject by way of spatial-visual enclosure, clinical medicine makes use of the extensive networks of electronic communication that pervade society today (Lyon 2001). This proliferation of the static panoptic model has been termed ‘distributed surveillance’ and ‘electronic surveillance’ and has been applied to information society at large (Lyon 1994). We argue here that distributed surveillance has come to fit clinical medicine particularly well, since it complements the notion of non-invasive medicine, i.e. the idea that medicine should strive to minimize physical intervention of the patient-body.

The second aspect relates to what Hille Koskela has described as the ‘other side of surveillance’ (Koskela 2006). The argument here is that digital networks not only facilitate clinical systems of telepresent monitoring but that they also prompt usages of surveillance technologies that are at odds with the initial purpose. Uploading one’s endoscopy on the Internet could thus for instance be seen as a strategy to regain agency over one’s scrutinized body and redirect the clinical gaze outwards to society.

Generating images for non-invasive treatment

During the last decades, the notion of non-invasive or minimal invasive medicine has come to be associated with the extensive digitization of health care supply. Non-invasive treatment has been propagated as the medical exploitation of information technology. An altruistic enterprise promoted by the well being of the patient. Despite its inherent economic motive, non-invasive medicine is regarded as the humanitarian phase of an otherwise rigid, technocratic reform that sees computers and computing as a universal panacea (Coiera 1998). Unlike hip terms like e-health, cyber surgery, virtual hospitals and digital doctors, non-invasive or minimal invasive methods do not suggest that medicine is doing away with the messiness of the body. Only that refined forms of treatment aim at diminishing the necessity for messy intervention.

Non-invasive medicine relates to issues of surveillance, monitoring and control in two ways, a visual one and a proliferous one. Firstly, because non-invasive medicine stresses the necessity to disrupt the body as little as possible during diagnosis and medical treatment, physicians are compelled to find new ways of gaining access to the bodily interior. This is mainly done by means of visualization. Through sophisticated vision systems, multiplex images of the body interior are projected on computer screens and video monitors. Secondly, due to the convertible and extensive nature of information technology, it is possible to transmit medical images back and forth through the digital networks of hospitals, clinics and laboratories. The body is thus made visible, convertible and proliferated at the same time. One could say that the clinical gaze today is inscribed in a different web of spatial, corporeal and visual relations than it was say fifty or a hundred years ago. Unlike the spatial gravity that determined the methods of open surgery and peephole endoscopy, digitization entails a dissemination of the body undergoing treatment and examination. It is this dissemination of clinical data that subjects the body to new forms of surveillance.

If the aim of non-invasive medicine is to reduce physical intervention with the aid of visual technology, then the overabundance of visual information in clinics today is determined by the urge to spare patients unnecessary pain and suffering. This is why laparoscopic surgeons, insert their instruments through tiny

openings made in the abdomen, rather than cutting the body open. Laparoscopic surgery leaves smaller scars on the body but a large amount of information on the hard drive. Likewise, the increasing use of wireless capsule endoscopy, for screening of intestine cancer, is considered less invasive than previous forms of endoscopic viewing (Moglia *et al.* 2007). However patient friendly, capsule endoscopy provides a documentation of the digestive tract that by far exceeds traditional endoscopic methods in detail, quantity and accessibility.

The upsurge in electronic image production for clinical purposes has yielded an abundance of patient information that demands ethical consideration. Because imaging technologies are so interweaved with the nature of computing, the moral issues implied have both to do with what the images depict and how the digital data, supporting the images, is handled and stored. In the former case, ethical questions are particularly related to the burgeoning field of neuroimaging, where brain scans are used as tokens of the mind and human identity (Dumit 2004; Illes 2003; Barron and Kim 2003). In the latter case, the Electronic Patient Record has spawned debates on how medical information is best kept in order to secure the integrity of patients. Due to the convertible character of digital data, Electronic Patient Records can include different kinds of information, making it a more powerful and manipulative instrument than paper-based archives (Fairweather and Rogerson 2001: 220).

Generally speaking, brain scans and Electronic Patient Records pertain to the same notion of non-invasive medicine. They may provoke different ethical reactions but are nevertheless grounded on the same principle; understanding the body and storing patient data by means of digital conversion. Contrary to the controversies surrounding the issue of human remains, non-invasive methods are ethically problematic by virtue of their mediated nature. Pervaded by countless forms of invisible matter – radiation, magnetic fields, radionuclides, contrast fluids, fibre optics – the body of non-invasive medicine is best characterized as a site that generates an enormous amount of raw data. It is precisely this data that makes it possible for clinical surveillance to spread its ocular nodes far beyond the attending patient. Two conclusions can be drawn from this. One is that the visual apparatus employed to document the bodily interior, produces data that lends itself to widespread circulation in clinics as well as in society. The other is that patient safety, visual technologies, and surveillance stand in a specific relation to one another; the lesser pain is inflicted on the patient, the more important the need for steady documentation of the body.

Domesticating diagnostics

William J. Mitchell has called our attention to the invisible web of signals that permeates twenty-first century society. Urban landscape has become all the more superimposed by an electronic topos, a virtual territory that we access by means of an increasing number of electronic devices and gadgets. According to Mitchell, these gadgets have become ‘extensions of our mobile bodies’ (Mitchell 2005: 182). They make up the technological accessory of daily urban life and merge our virtual and physical realities into a seamless whole. It is also the emergence of this new electronic habitat that has determined the spatial rearrangement of the clinical gaze. Adapted to the grid of information networks, the medical panopticon, previously confined to the spatial demarcation of the hospital, is digitally converted and diffused throughout society.

On the one hand, the relation between clinical gaze and patient-body is subjected to extensive mediation and dislocation. In most visual technologies today, the physiologically embodied gaze is preceded by automatic recording, physical registration that is digitally processed and displayed via software. It is only after thorough instrumentation that the eye of the clinician reads the body-data of the patient. On the other hand, the technological apparatus that translates vital signs into data tends to operate more closely to the patient. With Paul Virilio we could say that the infrastructure of information technology, has made it possible for the panopticon to intrude upon the vitality of the body proper (Virilio 1996: 100).

Digitalization, miniaturization and mediation have paved the way for what has been termed ‘healthwear’, the use of portable electronic equipment, for purposes of clinical monitoring. Healthwear are technologies that enable patients to manage their medication and keep an eye on their conditions at home or while at work. They are the medical equivalent of ubiquitous computing. Through cell phones and home computers, patients can easily plug in their healthwear and render the data accessible from the clinic (Bushko 2005). Healthwear like the MITHril system, a biosensor that measures pulse oximetry, respiration, blood pressure and blood sugar, are predicted to revolutionize medical health care in the 21st century (Pentland 2005). Like the non-invasive methods discussed above, healthwear are seemingly patient-friendly. They allow medical care to relocate from hospitals to homes, thus providing patients with less distressful ways of coping with their infirmities.

Despite the advantages of home-based nursing, healthwear are all too easily associated with the negative aspects of surveillance technologies. It is plain to see how they conjure up dystopian ideas of intrusion, control and 24 hour spying. As Lynsey Dubbeld recently argues, in order to provide a more nuanced picture of telemonitoring techniques in medicine, the users perspective will have to be taken into account (Dubbeld 2006). Healthwear technologies are only in their initial phase. More empirical studies will be required before we can appreciate just how patients experience the domestication of healthcare. This said, healthwear are a good example of how clinical observation, has adapted to the new digital infrastructure. Whether we choose to see them as internalizations of the panopticon, or merely techniques for self-examination, they are highly representative of the dissemination of the clinical gaze.

Exhibiting the panoptic eye

The amount of visual information produced daily in hospitals and clinics today fits well into the description of what is referred to as distributed surveillance and electronic surveillance. These terms do not only underscore the opaque channels through which data travels before given a visible interface. They also draw our attention to the wider cultural networks which medical visualizations are part of. The same registries that are used for clinical purposes are also redirected outwards into society.

Two examples of how medical imagery is distributed in society today are the surgical webcasts presented on clinical sites such as Karl Storz Endoscopy¹, and the endoscopic videos uploaded on Youtube. Apart from making clinical material available to a wider audience, Karl Storz and Youtube have nothing in common. They represent two different viewpoints on how the Web should function. The one, Karl Storz, attempts to make the public more favourably disposed to medicine by engaging with it through media. The other, Youtube, is a child of Web 2.0 and adheres to the concept of participatory culture, i.e. the belief that the public should be encouraged in actively shaping the contents of the Web (Jenkins 2006; Deuze 2006). Although the endoscopic footage presented on the two sites is similar – tissues illuminated by fibre optics – the images are framed in radically different ways.

Contrary to Youtube, Karl Storz is an authorized medical homepage. It is the clinic made present in cyberspace. Rather than a virtual reinvention of hospital medicine, it employs the Web as a medium to reach an audience outside the operating room. Moreover, because some of the operations that can be viewed on Karl Storz are actually live webcasts, they evoke images from medicine's past, when operations and dissections were performed before a seated audience. In this respect, live webcasts employ electronic networks to re-inscribe the clinic within the social sphere of globalized society (Thacker 1999). The image of the clinic conveyed through live webcasting is thus one in which physicians, patients, and audiences are highly mediated. Surgeons perceive the patient-body indirectly on their screens and screen-images are transmitted on the Web to an audience who can communicate with the surgical crew via e-mail; this is what Karl Storz refers to as an ‘interactive internet webcast’.

¹ <http://www.karlstorznetwork1.com>. Karl Storz Endoscopy is a manufacturer of endoscopic instruments, which was founded by the German practitioner Karl Storz in 1945. Storz invented new ways of illuminating the bodily cavities by means of cold light. The company still plays an active role in medical technology today.

Information technology may have dismantled the spatial principles, underlying the anatomical and surgical theatres of prior days. Undoubtedly, the bodies of surgeons, patients and the public no longer congregate within the perspective of naked vision. Nor does the spectacle of medicine today take place in the realm of God's omnipotent eye. This does not imply however that the panopticon should have ceased to play a role in medicine today. As illustrated in the aforementioned example, new forms of discrete visibility have replaced the fixed position of the all-seeing eye. Channelled through the networks of information society, the virtual clinic reaches a widespread and mostly anonymous audience. By partaking in the webcasts, searching through the Karl Storz archives and downloading endoscopic images and surgical videos, this widespread audience constitutes an important part of the new clinical gaze.

Given the proliferation of medical visualizations by means of digital technology and bearing in mind the ubiquity of computers in 21st century society, it is not surprising that images produced for clinical purposes crop up in non-medical locations. Since the launch of the video-sharing site Youtube in 2005, uploading videos and pictures on the web has quickly become routine procedure among a new generation of computer and cell phone users. Youtube has not only stimulated the circulation of low-tech images on the web and expanded the scope of visual motifs in late capitalist society. Along with reality TV it has prompted a use of surveillance technologies that is at odds with our ingrained notion of social control and public camera monitoring. The use of webcams for instance, has opened up the private domains of our lives and brought the public eye into our homes. In a similar manner, digital imaging technologies have rendered the privacy of our inner body accessible to far-reaching medical observation. As shown in the example above, the patient undergoing endoscopic examination and surgery, is easily subjected to the extended gaze of the virtual community. In other words, through live webcasts, the visual apparatus of the clinic is tantamount to the surveillance technologies used elsewhere in society.

However, just as webcams are employed in ways that are inconsistent with the negative meaning of surveillance, so are clinical videos re-contextualized and displayed in wholly different manners. Compared to the Karl Storz webcasts, the endoscopies that are made public on Youtube have more diffuse contours. Titles such as, 'Sexiest endoscope of all time', and announcements like, 'do you dare enter the world of the inside', underscore the sensational motive behind these posts. Laid out on the Web, these films play with our notions of private and public, of self-exposure and anonymity. While at the same time invoking the cultural legacy of the anatomized body, the endoscopies on Youtube invert the relation between seeing and seen, intact body and dissected corpse, so central to the notion of medicine since the renaissance onwards. Viewing the endoscopies that figure on Youtube, makes one wonder about the motif behind this will to expose oneself. How should one conceive the bodily ethos that underpins this form of self-examination?

In his book on the culture of surveillance, John McGrath suggests that the TV show Big Brother, can be seen as a way to explore what to do about surveillance in a surveillance-saturated society (McGrath 2004: 204). In accordance with McGrath one could say that the endoscopies on Youtube are telling of a body politic that makes the individual body constantly visible through networks of electro-optic registration. Monitoring the images taken by endoscopes is the clinical correspondent of surveillance cameras, webcams and speed cameras, a non-stop recording of organic processes, which, although meant for hospital viewing, is all too easily forwarded to the visual flux of media society. In the light of this, uploading one's own endoscopic video could be seen as a way to regain agency and control over the diagnosed/surveyed body.

The extended panopticon: monitoring population health

Much of biomedicine in the digital age extends beyond the level of an individual patient's body and operates in terms of statistical patterns of disease at aggregate levels. At the same time as the gaze on the body is intensified by technologies that exchange and convert data into images, a proliferation of information is taking place at yet another level, i.e. in aggregates of patient collectives and in population studies. At the centre of surveillance medicine, in the sense the term was introduced by Armstrong (1996), are biometric, statistical and visual techniques that render visible patterns of population health – the techniques used are those of the panopticon model of quantitative empirical science (Foucault 1975). Epidemiology – the study of distributions and determinants of health and disease in populations (Last, 2001) – plays a central epistemological role in public health. Epidemiological reasoning in terms of statistical patterns of health and disease is highly influential from the practice of clinical medicine to health policy. This plays out for example in the allocation of resources, decisions regarding treatment options as well as consultations in preventive medicine, where the risk estimates derived from population studies are applied to individual patients in order to reduce and manage risk factors.

Much of current medical knowledge production uses clinical trials, observations for patient collectives as well as epidemiological studies among the general population. The gathering of population data in ever increasing amounts can be traced back to the 19th rise of statistics that resulted in avalanches of statistical data in demography and throughout the life sciences (Hacking 1990; Porter 1986; Porter 1995). Since then the batteries of data recording and processing techniques have been continuously refined and extended. In order to provide knowledge on the effects of interventions and on risk factors at the population level for prevention studies, data on large collectives are produced. Many current epidemiologic methods, for instance survival analyses, build on methods for the analyses of mortality developed in demography. Recently, novel data have been generated in ever increasing amounts with genomics and molecular sciences and are included into epidemiological studies and clinical research. It is through numerical modelling and data visualizations, such as frequency patterns among different subpopulations, that these data become applicable. Bioinformatics has developed into an important discipline, when it comes to making sense of the complex data generated by -omics technologies and new imaging procedures; visualization, data mining and information design play an important role here (Fry 2004; Fry 2007).

The notion of evidence-based medicine and prevention has become a buzzword for a new way of thinking in the clinic and in public health. Evidence-based medicine ranks clinical knowledge according to the applied methods and aims at quantitative syntheses of clinical studies for decision-making. Similarly, in preventive medicine and health policy, so-called 'prevention trials' and survey data are drawn upon to allocate resources for disease prevention and health promotion. The quantitative evaluation and synthesis of epidemiological results is only possible if extensive monitoring programmes and investigations of patient populations as well as health surveillance of the general population are conducted. This entails a shift in medical knowledge from the physician's experience with individual cases to the level of large patient collectives evaluated with a statistical paradigm.

In order to explore further the shifts in the relation between the gaze, the body and space, the next section will focus on the production and usage of health surveillance data for epidemiological research.

In the observatories of epidemiology: databasing and modelling population health

Monitoring population health has a long tradition in demography, government statistics and social policy; in 18th century political arithmetic, population thinking, probability theory and the field of political economy were closely entangled (Desrosières 1998). The production of population data has long been intertwined with biopolitical frameworks, e.g. of central state governance, life insurance and actuary

reasoning. The panoptic constellation of monitoring and managing a collective ‘population body’ continues to play a central role in contemporary concepts and practices of evaluation and governance. In public health, surveillance, as defined by Alexander Langmuir, means ‘the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data’ for purposes of prevention of disease or injury’ (Langmuir 1992). Epidemiologist Alfredo Morabia described surveillance as the ‘bedrock of public health’ (Morabia 2000: 22); securing generation and access to valid data is critical in epidemiologic research.

Survey and monitoring techniques bring about statistical entities and make them perceptible; subsequent data visualization works as a tool for inspection of multiple aspects ‘at a glance’, similar to techniques of mapping. A survey is an act of viewing, examining and inspecting; the term ‘survey’ originated in 19th century land surveys and geology (Converse 1987). Different from land surveys for the mapping of geographical space, the data patterns visualized in epidemiology refer to multiple levels and diverse contexts.

The extent and modalities in which data are collected has differed between countries; often so-called ‘routine data’ such as demographic data on births and deaths (‘vital statistics’) are collected for the entire population. The Nordic countries maintain central population registries which allow record linkage between different sectors (for example population registries, social services and health care data). Health research relies heavily on data from these routine administrative monitoring techniques as well as on the data recording systems of health-related registries. Registry research has become a sub-discipline in epidemiologic research in the Nordic countries (Mortensen 2004). Further, specific epidemiological studies are usually conducted for representative samples of the population, for example longitudinal follow-up studies or cross-sectional surveys.

Health surveys among representative or random samples of the population are used to gain quick ‘comparative snapshots’ of the population’s health. Not only has the anatomic atlas of the macroanatomical body been replaced by a statistical and digitized body; at a population level health and disease are documented for instance in national cancer atlases, as done for example in Denmark since the 1970s. Visual mapping as part of descriptive epidemiology creates new epistemological infrastructures; the surveillant gaze takes up these new data patterns as grids of orientation, in which one is able to navigate. More than a metaphor the visual episteme plays a key to design and display of health statistics. Alluding to the objectivity effects of photography, Catherine Waldby has described epidemiological surveillance as an imaging process that is conceived to provide ‘accurate photographs of population health’ (Waldby 1996: 99). Graphs, charts and tables visualise and spatialize data; they mediate research design and risk communication.

While as part of state administrative procedures, routine data are recorded and stored to evaluate health and disease at the population level, it is also new forms of accountability that drive the implementation of monitoring and evidence-based decision-making; these in turn nurture the need for documentation, visibility and transparency. This data hunger of quality management has contributed to the vast bureaucracies that accompany medical practice and health care systems.

Surveillance as a tool and resource for epidemiological research

Epidemiologists often take advantage of exposure differentials across regions or time periods; they conduct a retrospective correlation and evaluation of data on exposures and health outcomes. For instance an epidemiological study on mobile phone use conducted comprised everyone resident in Denmark who had a mobile phone contract from 1982 to 1995 (Johansen *et al.* 2001). The database for the study was compiled retrospectively for that period, using data from the two companies that existed since 1982, when cell phone services had become available in Denmark. The data obtained from the companies, including

address, telephone system and subscriptions were linked with the files of the central population registry (CPR); this registry assigns each resident a unique CPR-number that allows record linkage between different administrative and social registries, including the registries of the health services system. The regulations in the Nordic countries allow epidemiologists to access data from the registries maintained as part of the social services and health care administration.

Denmark has a well-operating system of unique person-numbers, which has great practical significance in everyday life, and which makes it possible to follow the Dane 'from the cradle to the grave'. The basic data of the CPR can be linked to individual information about for example health, disease and occupational circumstances (Olsen *et al.* 2004: 1459).

With epidemiological methods, association studies are conducted as outcome research; a large array of potential determinants – as potential risk factors – can be connected with health data and expressed as probabilistic risk estimates.

In the mobile phone use and cancer study, the data of the 420,000 users were linked via their CPR numbers to the cancer registry, which contains data on cancer incidence for the Danish population. The authors of the study state:

Our study was based entirely on record linkage, and no one was aware of whether he or she was included. However, once the study had been announced in the media, the two telephone companies published in their quarterly reports a notice that subscribers could contact them if they wished to be excluded. A total of 53 persons contacted the telephone companies in this regard (Johansen *et al.* 2001: 204).

The early nationwide study on mobile phone use (showing no significant increases in cancer risk among mobile phone users) illustrates the ways monitoring data are used for evaluation purposes. Based on record linkage, researchers assessed the effects of mobile phone use, by taking advantage of the mobile phone data held by the companies and the registry data on cancer for the population living in Denmark. Health surveillance data are drawn upon for large collectives of the population and used for the purpose of an epidemiological study by state agencies, in this case co-funded by US and Danish research agencies together with the mobile phone companies.

The surveillance infrastructure allowed epidemiologists to combine data from different sources in order to evaluate in retrospect the introduction of new technologies. More generally, the option to extend and recombine existing datasets with new data from other contexts renders health surveillance data into highly productive infrastructures; this very local resource has been at the forefront of cutting edge research in epidemiology, often conducted in international collaboration. The epidemiological gaze on the population and patterns of disease are distributed between domains and actors, yet they can be connected via record linkage; this mode of data work builds on the panoptic gaze, albeit using distributed data.

Proactive modes of health surveillance

The previous example showed the epidemiological usage of data from telephone companies and population registries; in this case the use of government surveillance can be viewed as part of welfaristic principles of public health in combination with corporate data, performed in a top-down manner and taking advantage of the data routinely recorded for administrative purposes.

Yet, health surveillance can also take place in constellations that are not part of state bureaucracies but initiatives from below: The website 'WhoIsSick'² has been developed as a tool with which residents can

² Website 'WhoIsSick?' www.whoissick.org. Accessed: 15 June 2008.

monitor disease symptoms – from their own neighbourhoods to places they plan to visit. In a mode of proactive surveillance, this website assembles and displays information on health symptoms locally at the level of zip-codes connected to Google maps. The mapping software is setup to function worldwide, although use has so far been low and mainly restricted to North America. The website's mission reads:

Who Is Sick was started in 2006 with a mission to provide current and local sickness information to the public - without the hassle of dealing with hospitals or doctors. With a strong belief in the power of people and a faith that user generated content can be extremely valuable, our team set out to create an entirely new system for tracking and monitoring sickness in your area and obtain sickness information. [...] Given the relatively slower adoption of internet and 'web 2.0' technology by much of the healthcare industry, our team of healthcare professionals, technology entrepreneurs, mothers, fathers, and caregivers set out to create a simple, user-friendly, and valuable website for the average consumer (WhoIsSick 2008, online).

The story of its foundational idea is presented on the website as follows: Having stomach problems during a vacation, the initiator had to spend time waiting in a hospital just to learn that a flu was going around. To avoid such situations in the future, he decided to initiate a web-based tool in which users could monitor patterns of symptoms in the population by contributing information on their illness. According to the site, this web-based system of synoptic health monitoring is meant for the following use:

1. I am feeling a little sick and want to check what sicknesses are going around in my local area - probably within 10 or 20 miles from where I live or work.
2. I am traveling to another area of the country and want to know if there are sicknesses going around that I need to be careful of
3. I live in an area where I notice lots of people getting sick, so in preparation, I can take an AirBorne or vitamins to prevent catching anything (WhoIsSick 2008, online).

The envisaged use is a self-monitored life that navigates through the grids of potential health threats by avoiding contacts and sites of potential infections. Upon launch, the website prompted a number of reactions in the blogosphere: It was enthusiastically greeted as 'bottom-up epidemiology' and as 'a user-generated epidemiology map' by some web 2.0 enthusiasts³ and immediately dismissed as 'pseudoscience' for 'hypochondriacs' by other commentators⁴.

Designed to perform symptoms monitoring, the tool directs the gaze at patterns of aggregated data in order to enable overviews at a glance. Geographic space is enhanced by information on disease occurrence and time. The symptoms experienced by individuals are aggregated at a statistical level and plotted by region and time.

So far however, the tool does not seem to enact the collective gaze on population health: it currently displays patterns of usage rather than the symptom statistics the initiators were aiming at. Most entries come from major US cities, while the maps show only few singular entries in Europe and Asia. Even though envisioned as a grassroots epidemiological survey tool of population surveillance, the website does not provide the intended overview, as long as the tool is limited by low numbers of active users. When web 2.0 technologies are taken up for projects of watching and observing, the gaze upon the whole population requires a proactive participation by a large number of users. Independent of the tool's current function and validity, it however facilitates an augmented space in which individuals do navigate, build their lives around and create digital communities that volunteer for a symptoms surveillance project.

³ BoingBoing. A directory of wonderful things. Weblog <http://www.boingboing.net/> (<http://www.boingboing.net/2007/04/19/who-is-sick-usergene.html>). Accessed: 15 June 2008.

⁴ Medgadget. Weblog <http://medgadget.com> (http://medgadget.com/archives/2007/04/whoissickorg_hypochondriacs_welcome.html). Accessed: 15 June 2008.

Here, the population gaze is potentially made available to every internet user. Like self-diagnosis, this mode of health surveillance has left the medical and public health institutions and is conducted by individuals connected via the internet. This also presents a constellation where the individual citizen readily adopts the surveillant gaze upon the population's health. Thus, the traditional panoptic gaze on the body transforms into an oligoptic if not synoptic surveillant gaze that has entered popular culture.

With respect to epidemiological data production, not only by central health care systems but also the quest for transparency produces a 'population body' in digital data. Thus, these databases provide resources for state, corporate and individualized inquiries into health and disease as population patterns. Epidemiological techniques render visible and bring about population health as an epistemic object that can be mapped for public and governmental inspection. In this process, population health is performed via geographic tools that help navigate through space structured by patterns of self-reported sickness.

Conclusion

In this paper we have described how monitoring and imaging of the body and digital databases that contain data on population health constitute new forms of distributed surveillance. Likewise, we have shown that panoptic, oligoptic and synoptic modes of surveillance coexist in these new constellations of medical observation. Surveillance techniques play a key role in the monitoring of the individual patient-body as well as in the preventions and clinical decision-making of evidence-based medicine. As the digital technologies in data storage and linkage as well as web-based applications in biomedicine proliferate, the agendas with which surveillance technologies are applied have also become much more diverse. Surveillance is an inherent element of modern diagnostics. It is also a crucial mechanism in the governance of populations. However, in distributed form, individuals employ techniques of medical surveillance in order to actively make sense of their own bodies, for instance by using web-based risk mapping tools or uploading endoscopic clips on Youtube. The ways in which individual bodies and whole populations are continuously monitored for the purpose of diagnostics and health policy have brought about re-figurations of the body, space and the gaze. At stake here are different modes of participation in the surveillant gaze – both when it comes to individual patients' bodies as well as to the population health reasoning in epidemiology and public health policy. In distributed surveillance, in particular in web 2.0 applications, the 'imaginary of surveillant control' of governance seems complemented by an 'imaginary of participation'.

Acknowledgements

This paper has been developed in the framework of research for the Project 'Danish Biomedicine, 1955-2005: Integrating Medical Museology and the Historiography of Recent Biomedicine', funded by the Novo Nordisk Foundation, at the Medical Museion, University of Copenhagen, Denmark.

References

- Armstrong, D. 1995. The rise of surveillance medicine. *Sociology of Health and Illness*, 17: 393-404.
- Barron, B. J. and Kim, E. E. 2003. Ethical Dilemmas in Today's Nuclear Medicine and Radiology Practice. *Journal of Nuclear Medicine*, 44(11): 1818-1826.
- BoingBoing. A directory of wonderful things. Weblog <<http://www.boingboing.net/>>. [last accessed 15 June 2008].
- Bushko, R.G. (ed.) 2005. *Future of Intelligent and Extelligent Health Environment*. Amsterdam: IOS Press.
- Coiera, E. 1998. Four Myths about the Information Revolution in Healthcare. In J. Lenaghan (ed.), *Rethinking IT and Health*, London: Institute of Public Policy Research.
- Converse, J.M. 1987. *Survey research in the United States: roots and emergence 1890-1960*, Berkeley: University of California Press.
- Desrosières, A. 1998. *The Politics of Large Numbers. A History of Statistical Reasoning*. Cambridge MA: Harvard University Press.
- Deuze, M. 2006. Participation, Remediation, Bricolage: Considering Components of a Digital Culture. *The Information Society*, 22: 63-75.
- Dubbeld, L. 2006. Telemonitoring of cardiac patients: user centred research as input for surveillance theories. In: D. Lyon (ed.) *Theorizing Surveillance. The Panopticon and Beyond*. Uffculme: Willan, 182-205.

- Dumit, J. 2004. *Picturing Personhood. Brain Scans and Biomedical Identity*. Princeton: Princeton University Press.
- Fairweather, N.B. and Rogerson, S. 2001. A moral approach to electronic patient records. *Medical Informatics*, 26(3): 219-234.
- Foucault, M. 1973. [1963] *The Birth of the Clinic*. New York: Vintage.
- Foucault, M. 1991. [1975] *Discipline and Punish: The Birth of the Prison*. London: Penguin.
- Fry, B. 2004. *Computational Information Design*. PhD Thesis; Program in Media Arts and Sciences, School of Architecture and Planning, Massachusetts Institute of Technology. Cambridge MA (<http://benfry.com/phd/>) Accessed Aug 18, 2008.
- Fry, B. 2007. *Visualizing Data*. Sebastopol, CA: O'Reilly Media, Inc.
- Hacking, I. 1990. *The Taming of Chance*. Cambridge: Cambridge University Press.
- Jenkins, H. 2006. *Fans, bloggers, and gamers. Exploring participatory culture*. New York: New York University Press.
- Johansen, C., Boice, J.D, McLaughlin, J.K., Olsen, J.H. 2001. Cellular telephones and cancer. A nationwide cohort study in Denmark. *Journal of the National Cancer Institute*, 93(3): 203-207.
- Illes, J. 2003. Neuroethics in a New Era of Neuroimaging. *American Journal of Neuroradiology*, 24: 1739-1741.
- Koskela, H. 2006. The other side of surveillance: webcams, power and agency. In D. Lyon (ed.), *Theorizing Surveillance. The Panopticon and Beyond*. Uffculme: Willan.
- Langmuir, A. 1992. Public Health Surveillance. In W. Halperin, L. Edward, R. Baker, R. Momson (eds): *Public Health Surveillance*, New York: Van Nostrand Reinhold.
- Last, J. M. 2001. *A Dictionary of Epidemiology*. 4th Edition. Oxford: Oxford University Press.
- Lyon, D. 1994. *The Electronic Eye. The Rise of Surveillance Society*. Cambridge: Polity Press.
- Lyon, D. 2001. *Surveillance and Society: Monitoring Everyday Life*. Buckingham: Open University Press.
- McGrath, J. E. 2004. *Loving Big Brother: Performance, privacy and surveillance space*. London: Routledge.
- Mathieson, T. 1997. The Viewer Society: Foucault's Panopticon Revisited. *Theoretical Criminology*, 1: 215-234.
- Medgadget. Weblog <<http://medgadget.com>>. [Last accessed 15 June 2008].
- Mitchell, W. J. 2005. *Placing Words: Symbols, Space, and the City*. Cambridge MA: MIT Press.
- Moglia, A., Mencias, A., Schurr, M.O., Dario, P. 2007. Wireless capsule endoscopy: from diagnostic devices to multipurpose robotic systems. *Biomed Microdevices*, 9: 235-243.
- Morabia, A. 2000. Worldwide Surveillance of Risk Factors to Promote Global Health. *American Journal of Public Health*, 90: 22-24.
- Mortensen, P. B. 2004. Registerforskning i Danmark. *Norsk Epidemiologi*, 14(1): 121-124.
- Olsen, J. H., Mellemkjær, L., Friis, S. 2004. Fra kræfttælling til cancerregister. *Ugeskrift Læger*, 166(15/16): 1458-1461.
- Pentland, A. 2005. Healthwear: Medical Technology Becomes Wearable. In: R.G. Bushko (ed.), *Future of Intelligent and Extelligent Health Environment*. Amsterdam, OS Press.
- Porter, T.M. 1986. *The Rise of Statistical Thinking*. Princeton: Princeton University Press.
- Porter, T. M. 1995. *Trust in numbers: the pursuit of objectivity in science and public life*. New Jersey: Princeton University Press.
- Thacker, E. 1999. Performing the Technoscientific Body: Real Video Surgery and the Anatomy Theater. *Body & Society*, 5 (2-3): 317-336.
- Thacker, E. 2005. *The Global Genome. Biotechnology, Politics, and Culture*. Cambridge MA: MIT Press.
- Waldby, C. 1996. *Aids and the Body Politic. Biomedicine and Sexual Difference*. London: Routledge.
- Weghorst, S. J., Sieburg, H. B., Morgan, K. S. (eds) 1996. *Medicine Meets Virtual Reality. Health Care in the Information Age*, Amsterdam, OS Press.
- Who Is Sick. Website <<http://www.whoissick.org>>. Accessed: 15 June 2008.
- Virilio, P. 1996. *The Art of the Motor*, Minneapolis, University of Minnesota Press.