



Beyond Traces: Towards a socio-anthropology of digital health

Gérard Dubey

Institut Mines
Télécom/Télécom École
de Management

[gerard.dubey@telecom-
em.eu](mailto:gerard.dubey@telecom-em.eu)

www.telecom-em.eu

Abstract

Digital health technologies may first be characterized by great ambivalence. They reflect new modes of social emancipation while giving material form to new control methods (biopower, surveillance medicine) with certain well-known characteristics or features that have yet to be deciphered. Rather than being formal, such ambivalence is the starting point for our understanding of the social dynamics resulting from the use of health technologies. "Traces", which it is the overall aim of current technological apparatuses to collect, store and process, have a diametrically opposed meaning depending on whether or not they are construed as the outcome of a collective effort or underlying "political project". This article thus questions the various, often contradictory, significations that are induced by the use of domohealth and social networks.

Keywords

Digital health, home automation systems, social networks, anthropology, data, traces, control, user.

Le dessous des traces: pour une socio- anthropologie de l'e-santé

Résumé

Les technologies en e-santé apparaissent d'emblée marquées par une forte ambivalence. Expression de nouvelles formes d'émancipation sociales, elles matérialisent aussi de nouvelles modalités de contrôle dont certaines caractéristiques sont bien connues (biopouvoir, médecine de surveillance) alors que d'autres restent encore à déchiffrer. Cette ambivalence, loin d'être formelle, est le point de départ d'une compréhension des dynamiques sociales sous-jacentes aux usages de ces technologies. Les « traces » dont la finalité

des dispositifs technologiques actuels est de s'emparer, de stocker et de traiter, revêtent par exemple un sens diamétralement opposé selon qu'elles sont ou non le produit d'une élaboration collective ou d'un projet « politique » implicite. Ce sont ces différentes significations, parfois contradictoires, qu'interroge cet article à partir des usages de la domosanté et des réseaux sociaux.

Mots-clés

E-Santé, domotique, réseaux sociaux, anthropologie, données, traces, contrôle, usager.

Más allá de los indicios: hacia una socio-antropología de la salud digital

Resumen

Las tecnologías digitales de salud se caracterizan, ante todo, por una gran ambivalencia. Reflejan nuevos modos de emancipación social al dar forma material a nuevos métodos de control (biopoder, vigilancia médica) con ciertas características o funciones que aún deben ser descifrados. Esta ambivalencia es el punto de partida para nuestra comprensión de las dinámicas sociales que resultan del uso de estas tecnologías en salud. En lugar de ser formal, como la ambivalencia es el punto de partida para nuestra comprensión de la dinámica social que resultan del uso de las tecnologías sanitarias. Estos "indicios", que son el objetivo general de los actuales aparatos tecnológicos para recopilar, almacenar y procesar, tienen un significado diametralmente opuesto en función de si están o no construidas como el resultado de esfuerzo colectivo o un "proyecto político" subyacente. Este artículo cuestiona, por tanto, las diversas significaciones, a menudo contradictorias, que son inducidos por el uso de dispositivos automatizados de salud ("domosalud") y redes sociales.

Palabras clave

Salud digital, sistemas de domótica, redes sociales, antropología, datos, indicios, control, usuarios.

1. Introduction

The scope of public health spreads beyond the limits of medical expertise and the health establishment, where, until recently, it had been confined, extending out to the sensible, social or interpersonal experience of sickness, or even to the issue of well-being. This extension of the meaning of public health occurs coevally with the development of new health technologies. Sensors, home automation systems, objects connected to Big Data warehouses, smart textiles, social networks, mobile apps, augmented reality or robotic assistants draw our attention to the current flurry of objects and cross-disciplinary projects and to the expectations of professionals and non-professionals alike.

This observation rises a myriad of questions. Are we witnessing the beginning of a new era in the medicalization of society (Illich, 1975) or rather a new step in the de-medicalizing process of the healthcare industry? Is telehealth a response to the patient's claims and/or a more global trend towards security dynamics? How did or does technology, especially digital technology, help challenge the compartmentalization of knowledge and the related know-how, the doctor-patient relationship and the representations and norms applied to the sick and healthy body? Conversely, how does technology help reinforce knowledge division and established hierarchies?

Technology, in fact, may at first be characterized by great ambivalence. It reflects new forms of social emancipation while giving material form to new control methods, which we think we know already but whose characteristics will never cease to surprise us. The acknowledgement of this dichotomy, however, cannot be addressed in a purely formal way, as it is often the case, but it must be a starting point for our understanding of the social dynamics resulting from the use of health technologies.

For each of these interpretations of digital health, somewhat antithetical, "personal data" and "data collected from patients", among other expressions, convey many different meanings. "Traces", which it is the overall aim of current technological apparatuses to collect, store and process, have a diametrically opposed meaning depending on whether or not they are construed as the outcome of a collective effort and underlying "political project".

Automated medical care at home, also known as "Domomedicine", is the first issue addressed in this article. It illustrates how patient demand for autonomy gives rise to new forms of control. The focus on social media health networks, another key issue, highlights the implicit and explicit dynamics of emancipation resulting from the use of information and communication technologies. Employing these technologies most often equates to visiting large

commercial websites, such as Doctissimo.fr, or developing a consumerist attitude towards healthcare. This does not seem to reflect, however, the multiple and sometimes conflicting significations of these practices, which convey many different but intersecting, overlapping and sometimes colliding views of health, disease and their related modes of knowledge.

2. E-Health vs. Control: Towards participatory control

One of the key arguments in support of digital health, which is often referred to, is that it allows vulnerable people with chronic conditions, or simply facing the effects of aging, to remain in their homes for as long as possible. Digital health is promoted as a means to save patients visits to the hospital, a “dehumanising” environment which they see as a secure place, but also as a synonym for reduced autonomy and seclusion. This clearly shows that technological innovation is intended to meet society expectations. Indeed, one can recognize that digital health technologies inscribe themselves within the global movement of contemporary society described by Michel Foucault which aims to replace institutions that might qualify as “disciplinary” with increasingly flexible, diversified, personalized and mutualized modes of control (apparatuses) (Armstrong, 1995; Foucault, 2004; Gros, 2012).

From a historical standpoint, the development of these technologies coincides with the widening of the breadth of the definition of health, formally reflected in the Ottawa Charter (World Health Organization [WHO], 1986). The definition of health was indeed extended to include everything that helps improving the physical, moral and social well-being of people. Associated with the idea of happiness, health has come to encompass all human activities and transcend the biomedical approach to which, until then, it had been confined. This extension of health, however, may also be interpreted as a widening of the scope of control or as the continuation and pursuit of the rationalizing process through which society implements ever more rapidly the transfer of work-based technologies to people’s private or domestic space. From mediating tools promoting people’s social autonomy, these technologies have thus become change agents in transforming people’s homes, to the point of turning themselves into disseminated and disciplinary micro-spaces, losing visibility as they blend in with people’s private or domestic spaces.

In home automation projects, a first risk linked to this shift, perhaps the most important risk, comes together with the difficulty of distinguishing clearly between automated medical

care at home ("domomedicine") and automated health care ("domohealth"). Some devices, such as sensors used to measure and track motor activities and physical parameters in the patient's home (heart rate, blood pressure, temperature) are perceived as medical tools. Yet these devices also collect information about people's regular existence and provide insights into the privacy and intimacy of their homes (Beaumartin, 2014). Domohealth therefore contributes indirectly to considerably extend the scope of medical action by processing substantial amounts of personal or medical-social data. Surveillance and autonomy are thus entwined. The possibility for a patient to stay at home, which is meant to ensure his autonomy, results in the strengthening of the monitoring of his daily activities, but for other purposes.

To conceal the medicalization of private homes, or their apparent "functionalization", in other words to prevent these homes from eventually turning into what these apparatuses are precisely meant to conjure, discretion is recommended. As an industrialist from the health sector once explained in a conference on digital health: "to gain acceptance of these technologies, it is best to hide them" (Jetsan, 2014). Turning sensors all through people's homes into "invisible" or even "natural" agents, as telephone companies do with relay antennas for mobile networks, raises a number of questions on the mediating role of these connected objects. What is the point of manipulating, playing, diverting, reinventing or even acquiring that which has no existence, as such, and is only there as the air we breathe? The values of ambience and comfort seem to prevail over the use, or even user, values. It is indeed extremely important to avoid disrupting people's familiar and private environment. It is less so, however, when the purpose of home monitoring or collecting data from individuals is concealed. This reality about digital technologies in the age of Big Data and cloud computing is even truer in the case of domomedicine and domohealth. These technologies are involved in the implementation of new forms of control, less vertical, but all the more effective, at a normative level, because they inscribe themselves locally in people's familiar space (where confidence reigns), enabled to do so by individuals feeding databases simply by living a normal life.

3. Connected objects or tracking the lost user

In view of this, the first question we need to ask ourselves is perhaps not so much what the legal and ethical status of this insidious standard practice, or technical naturalising of it (Rouvroy & Berns, 2013) can be, although these issues are also of considerable importance,

but, rather, how these “camouflage” techniques prevent us from appreciating, taking the measure of, and, to some extent, deciding on the changes under way. A quick review of the research on connected objects, carried out by engineering experts, offers numerous examples of this kind of highly problematic way of defining our relationship with objects today. One example, in particular, is worth mentioning here as it sums up quite well the prevailing vision in the field of design. In an issue of *Cahiers du numérique* published in 2002, long before the deployment of connected objects in our daily life, Gilles Privat explained that

...the end point of the evolution of objects, which began with their proliferation and diversification, should be in fact their disappearance, and this is not a paradox. For the user, this will be a subjective loss because objects should ideally disappear behind the service that they provide, blend in with the user’s environment and eventually cease to be objects of attention and interaction. Expressions such as ambient intelligence, quiet and evanescent computing, attentive environment, context-awareness connote (...) this evolutionary step.(...) The fact that objects communicate with one another and with their environment amounts to keeping the user “out of the loop”, wherever possible, thus enabling objects to keep interacting all together. Typically, the information that will be gathered by means of sensors or through synchronization with other objects would have been collected “manually”, and thus acquired, by the user. If objects are designed to communicate with one another and with their environment, however, it is to avoid interacting with the user, when it is not required, thus increasing the bandwidth available for the user while eliminating by the same token any parasitic and redundant communication (Privat, 2002, p. 39).

In the late sixties, Jean Baudrillard was one of the first sociologists to report the changes under way. The concept of “ambience” was at the core of his demonstration. As Baudrillard wrote:

Because automated objects *work independently*, they bear a resemblance with autonomous human beings, and this fascination prevails. We are confronted with a new form of anthropomorphism (where) it is no longer the gestures, energy and needs of man that are projected onto automated objects but, rather, the autonomy of his consciousness, his control power, his own singularity, the perception of his being” (...) In fact, a true revolution has taken place in our daily life: objects have become more complex than man’s attitude towards them today. Objects are increasingly diverse while our gestures are becoming less and less differentiated (Baudrillard, 1968, p. 79, p. 157).

For Baudrillard, technical efficiency, thus freed from efforts, body energy and "life-size" realities, testified already to the scheduled elimination of the subject and...the user. The concept of ambience pointed out to a world of objects which had become autonomous while being considered as a new "natural environment". I develop a similar view in a recent article on connected objects and "smart technologies" (Dubey, 2014).

As regards digital health systems, it is essential to understand and describe most precisely how these apparatuses modify our perception, the scope of our experience and awareness of the world, of time and space, and our relationship with our immediate environment. The ancient and persistent representation of a private home, as an intimate space sheltered from the sight of other people, still prevails even though it has already become, at least partially, a thing of the past. "Wired", "embedded" or "connected" technologies are drastically changing the social status of a private home by opening it to the winds. Ensuring the safety of people in their homes has therefore the strange effect of blurring the refuge or shelter image usually attached to what we consider a "home".

The debate on the intrusiveness or invasiveness of health technologies and its corollary, personal data confidentiality guaranteed through technical means (see the normative reflection on Privacy by Design, for instance) always lags behind events. These technologies were meant to reduce all borders, so the debate should rather focus on the externalization of privacy and on how it transforms our experience of the world. One might also express concerns about the foreseeable user resistances to these technologies. Users' private environments, however, have been prepared for that. Their homes have been connected and opened "technically" (internet, telephony). Also, it has become customary for users to expose personal information about themselves or view their identity in relation to outside information, images and messages conveyed by the network.

4. E-Health vs. Autonomy

It is therefore clear that the issues raised by the integration of these technologies within people's private and intimate spaces, where rules other than those of the production sphere prevail, challenge our experience of the world and modes of knowledge relating thereto. Domohealth, for instance, compares with "Quantified Self" in that it helps familiarize individuals

with the principle of pervasive monitoring and the notion that they can only represent themselves from an external reference point or through information that are channelled back to them via technical apparatuses. This is also a way of experimenting containment. Indeed, "home" is conceived as a space that must be contained through permanent monitoring of output and input streams. It is as if minimising environmental contaminations and alterations is what best guarantees the integrity of individuals against the affects of illness. This nearly obsessive relationship with safety and the outside world, with its emphasis on vulnerability, frailty and deficiency, suggests that the needs for protection, or for heteronomous monitoring and control systems, are no less infinite than the potential threats to which any closed system can be exposed. Indubitably, this anxiety-generating type of biosecurity bears the mark of Foucault's concept of "biopower".

5. Traces and data

Digital health experiments, however, cannot be reduced to expressions of biopower or ways of internalizing its norms. Alongside the deployment and, most importantly, the social use of certain digital health systems, it is essential to consider the person and have respect for her experience, relational and historical dimensions. Data and information, as deviations between series, matter less than the quality of experience whose surface can only be skimmed by numbers.

Modern science and modern medicine established themselves, it is believed, on the basis of what the historian Carlo Ginzburg has designated as the "Galilean paradigm" (Ginzburg, 2010). In the Galilean tradition, all that really counts in essence, wrote Galileo in *Il Saggiatore*, are "figures, numbers and movements, but not smells, flavours nor sounds, which I believe are, apart from the living animal, nothing else but names" (Ginzburg, 2010, p. 255). That which is individual, we cannot speak about (*Individuum is ineffabile*). Ginzburg calls this other side of knowledge an "index system" that focuses mainly on marginal or infinitesimal indexes and individual cases, tracking traces and indexes which are part of our common knowledge but are also, to a large extent, research material for social sciences today.

The index paradigm gives meaning to the event through analogies and comparisons. For example, the appearance of a disease, which disrupts life, can be apprehended either through the knowledge of singular events that occurred in the life of the patient or through the links

that the patient was able to establish with his environment under the circumstances. Engineering sciences rely primarily on the first type of knowledge while social and historical sciences are concerned with the second type. Medicine is a special case as it stands in between. Historically, it has its roots in the first type of knowledge. However, medicine, we must remember, is also an art, so that a practitioner cannot treat a patient the way a pilot flies a cutting-edge plane: with instruments. Indexes or measurable and configurable data, which inform the modern practitioner about his patient's vital functions, are obviously crucial but they are only one part of the knowledge to be used. "Nobody learns the trade of medical expert or the art of diagnosis, thus wrote Carlo Ginzburg, merely to implement existing rules. Other tangible skills such as flair, intuition and keeping a sharp eye also come into play, as it is usual to say, with this type of knowledge" (Ginzburg, 2010, p. 193). The technification and hyper-specialization of medicine are recent phenomena indeed.

Yet, it is precisely the distinction between these two types of knowledge that has been eroded by digital health technologies, which have come to express or raise certain expectations. It is not the functionalities of these technologies, as such, that account for this erosion, but rather the contiguous relationship between formerly separate and incommensurable fields of knowledge that has been established, by force of circumstance, through these technologies (see Akrich & Meadel, 2004). One of the unexpected consequences of technologies focusing on health, autonomy and the patient within his environment is that it helps reinstating the second type of knowledge. It is, at least, one of the key findings reported from a recent survey on the use and representations of social media health networks (Broca, Craipeau, Dubey & Koster, 2011).

Health professionals often see the Internet as a tool to promote a consumerist approach to health. An example of this is the patient in a medical consultation submitting a pre-diagnosis to his practitioner which has been established on the basis of information collected from health websites. The terms of the problem, however, may be reversed. Medical knowledge has gradually been transformed into medical, specialized or "technical" information which is more or less disconnected from the physical body. One can talk about the relocation of knowledge from its original production point, namely the patient-doctor relationship. Medical "consumerism" may thus be considered as the outcome of the upstream commodification of both health knowledge and remote information and communication networks. It ensues that the possibility of transferring medical information to large commercial sites involves the prior degradation of the patient-doctor relationship, or lack thereof.

Conversely, the use of certain social media health networks (non-profit for the most part) reflects the evolution of sensitivities towards health and disease. Exchanges through these

networks attest to a shift in attention to the quest for means of supporting the vitality of patients in the context of ordinary life. The focus is then on relations and on the integration of particular cases as ways to tame the disease and help the healing process. The sharing of traces and information in this context invites us to apprehend the person in his relationship to the world, to his environment and to multiple social temporalities, but not as a closed and indivisible entity. Traces and information are indicative of knowledge building or as André Gorz reminds us "of practical abilities and know-how which cannot necessarily be formalized or codified. Most tangible knowledge on the body eludes any potential formalization. It cannot be taught but it can only be learned by doing, by training... this knowledge can only be passed on to others by the subject..." (Gorz, 2003, p. 38) whereas "data" represent an outsourced, disconnected and desocialized type of knowledge (Paulré, 2009).

The way in which individual or subjective experiences are brought together and shared today brings into view, as a side effect, a change in representing the disease or what is meant by being sick or vulnerable. Reintegrated into the social sphere, of which it is a special reflection, the disease thus makes sense by extending itself beyond the strictly medical and functional normative framework where it had been confined. One of the characteristics of e-health technologies in this process is their supportive role to act as a catalyst for building a non-expert and collective type of knowledge which is totally autonomous from established forms of biopower.

6. Towards a recognition of the plurality of knowledge surrounding the disease

Coming together with the transformation of our relations with the medical establishment, this trend, however, is less about challenging medical power in a straight-forward manner (as was the case in the 1970s), than asserting other types of knowledge which may be seen as alternatives to such power. Non-expert or "amateur" types of knowledge do not necessarily constitute alternatives which stand for or against established (or expert) knowledge, but rather they are based on life experiences occurring beyond the scope of the medical establishment. For instance, the chronicity of some diseases involves establishing complex healthcare pathways as well as alternating hospital stays with ambulatory care interspersed with periods of relative "normality" for the patient. These new experiences can now be acknowledged and discussed on

social media health networks.

The paradox is that such networks, as new spaces for signification, meet expectations that are not addressed by the medical establishment, but they also rely on the achievements and effectiveness of contemporary medicine. The course of chronic diseases and the ability to live longer with lethal diseases are part of the experience from which a reflection on the non-functional dimension of the disease has been developed. While the building of new knowledge on health reflects the loss of scientific legitimacy (and of the Galilean paradigm), it also attests to a growing feeling of defiance towards the institutions in charge of public health, indicating how society apprehends this knowledge and finds a new meaning to it.

Here we see the possibility for a new convergence of knowledge. Fundamentally, it is less a matter of acquiring medical knowledge than of recreating certain conditions for its emergence. The expectation, shall we say, is for medical knowledge to be re-localized or re-personalized. The disease should no longer be considered from a mere objective or functional viewpoint, but it should be looked at from the standpoint of the culture, singular biographical elements and "traces" of the patients through which they can relate to the world, engage and interact with their peers. Also, personal interaction with caregivers should not be undermined. The building of knowledge surrounding the disease, thus based on relationships, brings us back to a social and more qualitative definition of health which may be shared by health professionals, in their role as practitioners, as they never really resolved to give up on this significant aspect of their profession. A linkage between "expert" knowledge and "common" knowledge may therefore be established on the basis of their social conditions of production and from the fact that they represent a common reality.

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