

Datafication: the Flavor and Scent of Data

Lars Botin

Department of Planning, Aalborg University, Copenhagen, Denmark

Summary

This paper deals with data handling in health care on three distinct and different levels. The three levels can be classified in the following way: ethical level based on principles, political level based on negotiations and relations, and phenomenological level based on relation in between the physical and digital world. The paper takes an outset in a recent report, published in October 2021, from the *Lancet and Financial Times Commission on governing health futures 2030* (ethical level), and a recent publication (2020) and exhibition at the Biennale of Architecture in Venice (2021) on *Data Publics* (political level), and finally makes an attempt to frame our being with digital technology on a philosophical and phenomenological level. It is the assumption that all these levels are needed the moment we try to appropriate and incorporate data in different arenas and worlds, might they be global, national, institutional, or/and individual.

Keywords

Ethics, politics, phenomenology, datafication, e-health, flesh

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1 Introduction

In 2021, the Austrian pavilion at the Biennale of Architecture in Venice focused on what the curators Peter Mörtenböck and Helge Mooshammer coined as *Data Publics*. In their edited publication from 2020 they state that we must consider the *Public Plurality in an Era of Data Determinacy* [1]. The *Lancet* and *Financial Times* Commission released a report at the end of 2021, wherein they discuss how health futures can be perceived in an era of digital transformation.

The aim of this article is to discuss the analyses, arguments, and conclusions of these two contributions to the field of how we should/ought to deal with data in a way and form that assures values, ethics, and politics there to be constantly present. Beside discussing the two contributions to the field, I will introduce to a third approach on digital transformation, which is based in a phenomenological perspective on technology. In this way I try to open the box of flavors and scents of data, which are ubiquitously touching and moving/transforming our everyday life understanding and practices.

2 The Politics of Data

Mörtenböck and Mooshammer are explicitly promoting an alternative way of handling data that challenges the current neo-liberal and market-oriented approach. They claim that there is a false dichotomy in between individuals/citizens, organizations, states, and developers/suppliers when it comes to the concept of *property* and *ownership*. The moment we look at and treat data as a property (personal/state/market) we open for trade and commodification, which inevitably will be governed by the powerful players of

the market [1]. We act on the premises of the market, and the technological solutions that are developed by the market. They claim that the state/nation is under pressure in how digital realities and communities constantly are constituted and transcend/transgress borders and boundaries. These digital societies are plural, heterogeneous and transformative, and impossible to keep under control by regulations and laws by states or conglomeration of states like the European Union, because acting according to the rationale of the market, *i.e.* property and ownership. General Data Protection Regulations (GDPR) is an exemplary sample of that.

One of the slogans from the exhibition in Venice reads: *Data Is A Relation Not A Property*. We should consider data as a contingency, and a way and form of relating to world and other. “*If we accept that data is not at all a form of personal property, something that belongs exclusively to us, but is the result of a collective effort (commons), we can start to think about different forms of care and about different forms of institutions that can take care of these relations*” [1].

Within the framework of the commons, we are called to take care, and create institutional frameworks for care, which is diametrically different from personalized property focused digital caregiving and taking. Individuals will constitute in a variety of ways which is defined by how data relations perform in the common, or what the authors call the *public*.

The agenda of Mörtenböck and Mooshammer is, as I was saying political, and inspired by Michael Hardt and Antonio Negri [2] and Judith Butler [3]. Furthermore, there is a clear postmodern approach to the topic, see Jameson [4] and Deleuze and Guattari [5], which means that they conceive the world and reality as fragmented, heterogeneous, and characterized by

dynamic flow of constant becoming. I shall return to Mörtenböck and Mooshammer's conclusions, and for now move on to the *Lancet* and *Financial Times* report on digital transformations approaching 2030.

3 The Ethics of Data

The report on digital transformation approaching 2030 is an extensive work on how children and youth should be targeted when it comes to future digital transformation. I shall leave this focus out of this discussion, and deal with the overall analysis and conclusions. There are 20 researchers from all over the world behind the report, and in this way the focus on Universal Health Care through digital transformation within health-care is covered. The report is an outcome of classical modern ontology, with concepts like universalism and homogeneity, and principles stemming from mainly Western understanding of ethics. The report classifies five principles that should be addressed when we think digital transformation and how the digital ecosystem should perform: democracy, equity, solidarity, inclusion, and human rights. The authors state that the most important (on a global level) is solidarity, and in this way, there are some affinities to the framework of *Data Is A Relation*, because the report is overly focusing on how to create solidarity and equity through digital transformation, where marginalized, underprivileged, weak and minorities are favored on behalf of those in power, and the majority in general.

The report is criticizing how digital transformation has been thought and performed in Western societies, since the becoming of digital technologies: *“As new technologies are progressively introduced and replaced, the boundaries of digital transformations in health and health care are pushed forward at an accelerating pace, often without concern for their public purpose or the effects on equity and human rights”* [6]. On several occasions the report addresses the problem of pace and acceleration as something that enhances and enforces the divide in between the already empowered and the already disempowered. The report does not give in-

dications on how to deal with the exponential pace and acceleration of digital technology, beside stressing that measures have to be taken on a strategic, systemic and global level, bearing in mind that ‘local realities’ has to be considered when things are implemented.

These strategies are basically as follows: *“First, we suggest that decision makers, health professionals and researchers should consider digital technologies as increasingly important determinants of health and address their interactions with other determinants. Second, we emphasise the need to build a governance architecture that creates trust in digital health and enfranchises actors at all relevant scales. Third, we call for a new approach to the collection and use of health data based on the concept of data solidarity, with the aim of simultaneously promoting individual rights and public value. Finally, we urge decision makers to invest in enablers of digitally transformed health systems”* [6].

The second and the third point is clearly pointing at values that can drive a possible intervention in digital transformation. Trust and solidarity are needed the moment that this strategy should have some resonance in the system and among users. To create trust on a national level: *“...governments must go beyond issues of data privacy, freedom of expression, and harmful online content. They must ensure responsible and ethical technology development through robust and participatory regulatory and accountability frameworks”* [6]. It remains rather unclear what is meant by the latter part of the statement, besides: *“...strong rules and practices around accountability, transparency, respect for the rule of law, and equity”* [6].

In the same way that Mörtenböck and Mooshammer addresses the importance of the common and ‘collective effort’ in relation to care and care institutions, we find that the report in addressing a ‘new social contract’ emphasizes the importance of leaving the rationale of economy and market-driven geopolitics: *“The world must thus act urgently to address global power asymmetries through a digital commons architecture that addresses data extraction. Digital cooperation should support a greater shift towards a vision of health data and data for health that is based on data solidarity”* [6]. Where Mörtenböck

and Mooshammer reads the collective effort and the common as something that becomes through interaction in transnational communities with some confinement in relation to beliefs, desires, and thoughts, then the report is trying to set the framework on a national and global level, where it is the institutions that govern and control the paradigmatic movement in the digital ecosystem. In this way it is a top-down model, where fixed values have been set and frameworks and requirements are created with an outset in these pre-established and allegedly universal values.

4 The Phenomenology of Data

Mörtenböck and Mooshammer is in their postmodern approach critical towards pre-established principles and truths, and as if ‘bodies’ constitute through collaboration and interaction then also values and common beliefs are co-created. If we are willing to be relational and not consider data as our property, then data will eventually open for new ways of being together and be foundational for structures and architectures we erect for care to be designed and performed on a macro-level. Long time ago in the 1960'ies the Canadian thinker Marshall McLuhan wrote that: *“...the effects of technology do not occur at the level of opinions and concepts but alter sense ratios or patterns of perception steadily and without resistance”* [7]. McLuhan was talking about media-technologies like the television, the forerunner for current digital technologies. The working of information and communication technologies (ICT) and digital technologies is profound and constant, and the ‘physicality’ of data ought not to be underestimated when we consider how and in what way were are together with digital technologies.

On this note it is worthwhile to introduce to the work of the French philosopher Maurice Merleau-Ponty, whom in *The Visible and the Invisible* (1968) elaborates on the concept of *flesh*. In order to understand Merleau-Ponty's concept of the ‘flesh of things’, which is how we relate to world as being fleshy as well, then he introduces

the physiological and linguistic figure of the chiasm: "...the idea of chiasm, that is: every relation with being is simultaneously a taking and a being held, the hold is held, it is inscribed and inscribed in the same being that it takes hold of" [8], we are held by technology as we hold it, and the inscriptions on both the held and the holding are reciprocal, even though they are not echoing each other. The other (me) that is present in the digital world is not synonymous or echoing the physical me in analogous space, but we share through the fleshy qualities of both realities a common ground for action and understanding [9]. The internal chiasmatic relation is not necessarily harmonious, it can be alienating and perform as a rupture, nevertheless it is always already relational.

The German sociologist Hartmut Rosa has dealt extensively with how we relate to technology in late-modern society and world. He classifies our relation to technology as diagonal and uses the concept of resonance to understand this relationship. He identifies three axes: horizontal (humans-humans), diagonal (humans-technology), and vertical (humans-metaphysics). The diagonal axis of resonance is characterized by a 'deep' sense and feeling of being connected to the world through and with technology: "When we have repaired, altered, cleaned, or manipulated an object (e.g. a moped, a computer, a sweater) many times over, we and/or our idiosyncracies have literally become part of it – just as, conversely, it has become part of us and changed us" [10]. Basically, Rosa is resonating Merleau-Ponty's chiasmatic conceptualization of the relationship, and at the same time pointing at the transcendental mediating capacities of the relationship, because as a diagonal combining the horizontal (humans/societies) with the vertical (metaphysics/religion/art).

5 The Life of Data

Returning to the topic of this position article and try grasp the essences of data on different levels, then it becomes readily apparent that there are clear clashes and controversies in the arena of specifically *big data*.

Big data is characterized by harvesting information from a multitude of sources. These sources are often anonymized, standardized, generalized etc. in the process of becoming 'big'. Extraction of knowledge from big data overly ignores the process from origin, provenance and/or stock, and the flatness and one-dimensionality of the subsequent extractions are non-sensical, blind and in some cases even harmful to those from whom the original data were taken. How do we in the process of harvesting data cherish and nurture the origin of the source, *i.e.*, the individual as citizen in all its guises, might that be professional/expert, user, consumer, patient, relative etc.?

The answer to this rhetorical question is in its essence heterogenous, multiple and multistable, because the flavors and scents of ancestry are non-essential and bound to how individuals experience the corporal and embodied appropriation of everyday-life. How do these heterogenous essences emanate and permeate from personal lived lives to the strata of frozen digital homogenous surface? How do we prevent crystallizations from this surface produce harm and injure the bodies from which the data were originally harvested by the machines of big data?

It is beyond questioning and doubt that big data and Artificial Intelligence is producing results and solutions that are of enormous importance and help for all on a systemic level, might that be political, institutional and organizational. These mega and meso 'bodies' would be paralyzed and mal-functional if we did not have the data delivered, analyzed, processed and evaluated by different kinds of technology from the technologies of 'quantified self', measurements and samples on/of the individual. Mörtenböck and Mooshammer pointed out that if we perceive and frame data as property then the rationale of exploitation would prevail on all levels, individual, institutional, national, and global. If we, as the Commission advocate, set up a fix and static ethical framework for strategical handling of digital transformation then we would just echo/repeat the existing hegemony of Western thought, practices, and belief in science as propeller of society and world.

Data as relation and mediating force in between actors is political and existential. We are in the flesh of things, and we become flesh through and with things. This happens in myriads of ways, and multiple and multistable constituencies become in fluid and dynamic processes. Nevertheless, we are in a position where we can set a critical and constructive framework for our being with digital technologies.

In 2015 the European Commission initiated *The Onlife Manifesto. Being Human in a Hyperconnected Era* and in the manifesto is echoed what has been dealt with in this article: "*The development of a critical relation to technologies should not aim at finding a transcendental place outside these mediations, but rather of how technologies shape us as humans, while we as humans critically shape technologies*" [11]. The manifesto also bears notion of the false distinction in between private and public pointing at the fact that things are blurred, and the blurriness is a quality that has not been addressed so far. We still carry the belief that: "...the private is associated with intimacy, autonomy, and shelter from public gaze, while the public is seen as the realm of exposure, transparency and accountability. This may suggest that duty and control are on the side of the public, and freedom on the side of the private. This view blinds us to the shortcomings of the private and to the affordances of the public, where the latter are also constituents of a good life" [11].

In relation to the question concerning inequity, injustice, solidarity, fairness, empowerment and hopefully emancipation [12], then this becomes a matter of contingency between different strata and realities, from the individual level to the global. We should create spaces for relational constituencies, where exposed, weak, and marginalized people can become in variable and multiple ways. There is no one size fits all, and the private/personal should not be privileged on behalf of the public, and vice versa.

Another slogan from the Austrian exhibition in Venice is that: *The Future Is Public*. I agree upon that just if the public is the result of relational socio-technical configurations, and not a set framework of control, transparency, and accountability.

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Correspondence to:

Lars Botin
E-mail: botin@plan.aau.dk