

Monitoring the Self: Negotiating Technologies of Health, Identity and Governance

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## ABSTRACTS

### Session 1: Wednesday 11:00-12:00

Minna Ruckenstein (University of Helsinki): *Co-evolving with self-tracking technologies*

The talk offers a quick overview of the datafication of clinical practices and self-care by way of the three thematic areas that we associated in our review article with certain methodological and theoretical commitments (Ruckenstein & Schüll, 2017). Research on 'datafied power' focuses on questions related to economic exploitation, surveillance and biopolitics. The second thematic area 'living with data' explores data practices and data sociality, or self-fashioning through data, and the third concentrates on 'data-human mediation', studying the agencies of the nonhuman, including device features, algorithms, and data infrastructures. By building on this work, I present findings from a longitudinal study of the Danish Quantified Self (in collaboration with Dorthe Brogård Kristensen). By attending to how technologies energize people's aims, but also how they are experienced as limiting the everyday, we demonstrate how people co-evolve with self-tracking technologies. The technological capabilities participate in the transformation of self-experience: some aspects of the self are amplified while others are reduced and restricted. We discuss how technologies aid in raising the consciousness of agentic capabilities in a practitioner and heighten awareness of human intentionality, thereby indicating that the use of tracking technologies is inscribed in, but also runs counter to, the larger political economy landscape.

Harley Bergroth (University of Turku): *Dis/assembling self-knowledge: On paradoxes of knowledge production in proactive self-tracking*

As proactive self-tracking technologies are often presented to help individuals to better understand – and possibly adjust – their everyday patterns of being, self-tracking practices are typically narrated and analysed as means for self-related knowledge production; for gaining insight. What often attracts less attention is the tendency of self-tracking practices to effectively disassemble the experience that we may call self-knowledge.

This presentation draws from interviews and observations with Finnish self-trackers. It keeps an eye on the persistent tensions between experiences of knowledge and uncertainty, and elaborates on how systems of self-tracking in practice effectively produce their purpose as technologies of knowledge production. The logic of dis/assembling self-knowledge in everyday self-tracking is discussed theoretically in terms of how selves become lived as ephemeral temporal objects. This helps to see how self-tracking systems actively attract tight attachments and repetition. Yet, it may also open up avenues for thinking about the emancipatory affordances of systems of self-tracking further.

Session 2: Wednesday 13:00–14:30

Eloisa Stella & Cristian Leorin (Associazione Novilunio Onlus): *On the anthropology of eHealth: The troubling case of the aging population*

Since 2004, the European Union has set an impressive eHealth action agenda to tackle the societal challenges posed by the growing ageing population. However, over the years only a few success stories have emerged, whereas a vast amount of initiatives has failed and sunk major investments. Among the possible explanations, eHealth specialists continue to resist the need to get as close as possible to the beneficiaries of their technologies to address the areas of ignorance that may limit the effectiveness of their work. This practice appears especially common when the projects or products address senior citizens. In fact, most eHealth solutions produced for the “senior market” appear not only unsuitable but also biased by generational observing heavily influenced by ageist and medicalized stereotypes. Moreover, the technologies spawning from this culture either reduce older adults to passive subjects that must be surveilled and “managed” or promote one-size-fits-all models of “active and healthy ageing” that are neither sustainable nor respectful of individual dignity and subjectivity. The objective of this presentation is to fill the gap in understanding through the lens of the anthropology of eHealth. As independent experts of the European Commission, eHealth project partners and researchers, the authors will provide an ethnographic perspective on the variety of everyday practices and social forces that shape the current state of the art of eHealth technologies across Europe.

Chris Till (Leeds Beckett University): *Self-monitoring, agnotology and reflexive work*

In this paper I will propose a provisional theoretical approach to analysing self-monitoring which is approached as part of broader governmental rationalities which combine concerns with the biopolitical and the psychopolitical. I suggest that in an era of digital politics and digital capitalism the governmental strategy which self-monitoring reflects is one built on principles of “reflexive control” and “agnotology”.

While self-monitoring uses biopolitical strategies which target bodies and seek to maximize the physical capacities of the population for productive purposes they are equally (perhaps primarily) engaged with psychopolitics. The level of intervention is primarily on training the mind rather than the body. Moreover, such systems are built on the principle that the most effective method of such an intervention is to act below the level of consciousness; on habit formation and reflex responses. Thus they are analogical with “psy-ops” strategies such as “reflexive control”.

This strategy of intervention also makes them consistent with a fundamental aspect of digital capitalism; that it is “agnotological” or based on confusion, misdirection or obfuscation. The principles on which many self-monitoring systems are based do not require, indeed would be hindered by, users understanding the workings of the system. Their effectiveness is predicated on automated habit building (encouraged by feedback loops) and network effects, both of which are largely outside the comprehension of the individual. The systems of value generation which underlie these commercial enterprises are also obscured.

I will present self-monitoring systems as enabling the transmission viral control into our corporeality by using “nudge” based systems of behaviour change with the aim of creating “automatic subjects” who respond to stimuli in the desired fashion. We must therefore see the sociotechnical assemblages enabled by mobile tracking devices as “biopolitical” and “psycho political” interventions. While users potentially benefit from the development of healthier and more productive lifestyle regimes they are also being physically and psychologically reshaped to be more efficient cogs in the semiotic machinery of capitalism. Knowledge, data and semiotic driven production requires affective as well as material and immaterial labour necessitating efficient channelling of physical and psychic energy in order to remain productive.

Venla Oikkonen (University of Helsinki), *Ambiguities of race in genetic ancestry tests*

Commercial genetic ancestry tests are typically marketed as a way of establishing roots in evolutionary past where traditional forms of family genealogy cannot reach. In both popular and critical commentaries, the cultural appeal of ancestry tests is often linked to the perceived ability of the tests to fix a person's roots in specific ethnic and geographic locations. Reflecting this view, many have criticized genetic ancestry tests for reinforcing essentialist ideas of racial difference. My paper approaches genetic ancestry tests from a somewhat different angle. I propose that the cultural appeal of genetic ancestry tests arises largely from the ambiguity of race and racial differences in testing practices. Through examples from genetic testing websites and media texts, I show how race is enacted in multiple and mutually contradictory ways in different types of tests – admixture, mitochondrial DNA, Y-chromosome DNA – and how race is relational rather than fixed. This ambiguity enables mutually incompatible political and communal projects to invoke and engage the idea of genetic roots. Crucially, the fact that race is enacted and relational in genetic ancestry tests does not make the tests politically innocent. Quite the contrary, the ambiguity of race in genetic testing is a key site where politics are operationalized and negotiated.

Session 3: Wednesday 15:00-16:00

Hannele Harjunen (University of Jyväskylä): *Neoliberal bodies and the body weight monitoring*

Measuring, monitoring, and keeping a record of the measurements of the body are among the typical techniques of biopower that governments use to manage and control their populations. Body weight has for a long time been one of the most every-day targets of biopower. The weight of the body becomes an object of biopolitical interest from early on and continues throughout life. Measuring and monitoring are techniques off biopower by which people are taught the boundaries of the normal body and how to monitor these boundaries. As a biopolitical project, teaching about acceptable dimensions of the body seems to have been successful particularly in Western societies. Most people, especially women, know their basic measurements, especially their height and weight. This personal knowledge of the body is part of required know-how of the modern "health citizen" who has internalized the principles of self-monitoring. In the age of neoliberalism, biopolitical control is neoliberally attuned. The principles of neoliberal governmentality, e.g., marketization and economization of health, extensive responsabilization of the individual and promotion of the entrepreneurial approach towards the self are discursively transferred onto the notions of the healthy body and part of the every-day body management. Technologization of the body management seems to give tools and enforce this development. Self-measuring technologies have assisted in making monitoring of the body weight as an omnipresent, continuous task, and obligation. In this paper, my intention is to explore the discursive ties between body measuring technologies, (gendered) self-management of the body weight, and neoliberal governmentality.

Alvaro Martinez Lacabe (University of Roehampton): *Producing the self in the biomolecular HIV prevention era*

In the past six decades, the gay population from many western liberal democracies has gone from being a subject of abjection and necropolitics (Bersani 2010) to become a valuable resource in those liberal democracies (Puar 2007; Edelman 1998). This radical departure has its origins within a framework of implementation and development of neo-liberal doctrines and systems, in which the assimilation and control of the gay population is achieved through governmentality processes. Some of the most notorious forms of gay governmentality include: (i) social and institutional movements to establish gay marriage, (ii) the inclusion of the homosexual subject in the armed forces and (iii) the adoption and promulgation of pharmaco-

regulatory practices in the realm of HIV and AIDS. By pharmaco-regulatory practices I propose a double concept. Firstly, it involves the self-administration of Truvada. This is the personal dimension concerned with technologies of the self, the care of the self. Secondly, I refer to a set of dynamics that entails the targeting of the gay population as one of the main beneficiaries of Truvada and Pre-Exposure Prophylaxis, plus the dissemination of PrEP carried out by a multiplicity of knowledge-production agents within the HIV assemblage, plus the attempts of implementation of this pharmaco-regulatory practice. This dimension has to do with the control of populations many times through discourses on risk, pleasure, intimacy, personal responsibility. This presentation will focus on the role of antiretroviral drugs in the production of new forms of subjectivities.

#### Keynote 1: Wednesday 16:30-18:00

Celia Roberts (Lancaster University): *Handbags, spit and hair: Where is biosensing taking us?*

This paper uses examples from the work of members of Lancaster University's Living Data Research Group to explore contemporary biosensing practices. Referring to a range of examples, from ovulation biosensing and personalised genetic testing to cortisol monitoring, it will examine how normative assumptions about gender, sexuality, bodies and human relations are built into biosensing devices and related systems. The paper will also discuss the ways in which biosensing practices can disrupt or trouble such social norms. Additionally, reporting on a citizens' panel undertaken by the research group, I will explore important concerns about the ways in which biosensing might be changing people's relations to their bodies, to medical expertise and to intimate and non-intimate others.

#### Session 4: Thursday 9:45-10:45

Ayo Wahlberg (University of Copenhagen): *Tracking failing biologies*

Our biologies are constantly failing us, whether metabolically, immunologically, cardiovascularly, hormonally, neurologically or genetically. Such failure can span critical organ failure and uncontrolled cell division to milder aberrant immune responses that cause allergies. In this paper I use the notion of failing biologies to explore how living with (especially chronic) disease – morbid living – has come to be understood as a series of constraints, limitations, discomforts and/or apprehensions which impinge on daily living. Human biology is seen to fail individuals when, for example, impeding reproductive (or other) desires, diminishing quality of life or shortening lifespan. As a consequence biomedical treatments often aim to arrest the (progressive) biological failure that can lead to the tissue damage that ultimately will impinge on an individual's (not to mention his or her family's and loved ones') daily life to greater or lesser degrees. If treatment is available and accessible, such conditions as cancer, kidney disease or diabetes can in many cases be managed giving rise to, what we might think of as disease-specific, kinds of living. Millions of patients lead chemo-lives, dialysis-lives, ARV-lives or insulin-lives characterized by particular rhythms, disruptions and impairments and are consequently able to (chronically) live with their disease for years if not decades. In some ways, the chronically ill might be conceived of as pioneer self-trackers as for decades they (and loved ones) have monitored their CD4 counts, creatinine levels, blood glucose levels or Mini Mental State Exam score. Such disease markers can shape the kinds of living that follow in the wake of failing biologies.

Ingrid Young (University of Edinburgh), *Disease identities, HIV treatment and public health citizenship*

There have been major changes in HIV science over the past decade. On the basis of multiple, randomized control trials, it is now known that existing antiretrovirals (ARVs) used to manage HIV can also: prevent HIV

acquisition when taken as PrEP (pre-exposure prophylaxis) by HIV-negative individuals; and prevent onward HIV transmission when people living with HIV who have an *undetectable* viral load. That HIV treatment *is* prevention has had major ramifications for HIV policy and care, not least the need for regular and often frequent testing and/or monitoring of bodies, with some bodies monitored more closely than others. Drawing on qualitative data, participation in clinical discussions and health promotion materials in a UK context, I want to reflect on the changes in HIV science and their impact on a notion of biological – or more specifically - public health - citizenship. I want to pay particular attention to if, how and where the rhetoric around risk, identity and responsibility for health has shifted in relation to HIV treatment. Where people living with HIV have always been under intense social and clinical scrutiny, the significance of viral load monitoring and the link to population level public health interventions raises new and significant questions around surveillance, identities and citizenship.

#### Session 5: Thursday 11:15-12:45

Laetitia Della Bianca (University of Lausanne): *The cyclic self: an analysis of self-fashioning practices via menstrual tracking apps*

This paper focuses on the social shaping of fertility-tracking apps and biosensors that aim to monitor women's menstrual cycles by predicting ovulation; these are marketed to women trying to get pregnant ('reproductive use'), avoiding pregnancy ('contraceptive use'), and/or willing to learn to know their body and menstrual cycles ('cognitive use'). Such monitoring technologies have recently begun to get social scientists' attention, who successfully demonstrated, through critical discourse analysis, how these devices tend to reproduce gendered stereotypes, in terms of reproductive heterosex imperative (Wilkinson, Roberts, & Mort, 2015) or in terms of incentives towards the continuous production of data about one's fertility (Lupton, 2015). However, the way these technologies are handled in practice remains so far mostly unknown. In this paper, I show how knowledge about the (potentially) ovulating-self is enacted in practice; based on a praxiographic approach (Mol, 2002), I describe multiple versions of knowledge – 'natural', 'algorithmic', and 'experiential' – that people produce and mobilize when confronted to the material agency of these devices, that aim to unveil the inner machinery of an essentially hormonal body. The empirical material is constituted of field notes, semi-directed interviews (mostly with designers and users), grey literature and 'lively' apps content analysis (Lupton, 2016). The general objective is to demonstrate how shifting attention to practices instead of representations allows us to take into account the complex and continuing negotiations (adaptation, resistance, subversion, repurposing) between users, designers and technology.

Josie Hamper (Queen Mary University of London): *"Getting the timing right": Women's uses of fertility tracking smartphone apps*

Smartphones are increasingly entangled in the most intimate areas of everyday life, providing fertile ground for the continued expansion of digital self-tracking technologies. This paper will present research on women's use of smartphone applications, also known as "apps", to monitor their fertility with the explicit intention to conceive. This research is framed by feminist perspectives on reproductive technologies, and it engages with conceptualisations of apps as culturally and socially embedded. Fertility apps are multifaceted technologies that bring together aspects of self-tracking, social networking and diverse knowledge systems to offer a virtual tool for measuring and producing knowledge about the reproductive body. Drawing on empirical data from interviews with women in the UK and visual material from select apps, this paper will explore how participants used their apps to visualise, make sense of and respond to their individual menstrual cycles and predicted "fertile window". In particular the "fertility awareness" that these apps claim to facilitate will be critically considered; including how this awareness did or did not come about through practices of fertility tracking, and how the sharing of fertility knowledge with male partners (or lack thereof) demonstrates the

gendered dynamics of reproductive work. Investigation into these points reveals a complex and highly demanding cultural context of reproduction.

Celeste Orr (University of Ottawa): *Contemporary eugenics: Preimplantation genetic diagnosis, anti-intersex selection, and reproductive "choice"*

Preimplantation Genetic Diagnosis (PGD), a genetic screening technology that can accompany IVF, was originally developed to circumvent fatal genetic diseases. Currently, PGD is used to test for and select against nonfatal, but culturally devalued traits deemed inherently disordered and disabled, including intersex variations. Analyzing the discourses surrounding interphobic PGD usage, I demonstrate that this practice is a form of "new" eugenics (Campbell 2000). "Old-style" eugenics are characterized by state institutionalized racial, ability, and national "improvement." New eugenics are narrated through seemingly apolitical/objective medical terminology and notions of health, welfare, normality, good parenting, and free choice (Crowe 2000). That is, from old to new eugenics, there was a discursive shift from state welfare to individual welfare, from state-monitoring to self-monitoring. In legal, medical, bioethical, and fertility clinic literature intersex traits are referred to and regarded as innate disorders, disabilities, defects, and diseases (Sparrow 2013; O'Neill and Blackmer 2015). This literature also suggests that (potentially) pregnant people can freely choose against said pathologies (Trafimow 2013). This is quintessential new eugenic rhetoric; it exploits and reproduces ableist sentiments (Orr 2016) and, in turn, creates a moral imperative to self-monitor one's (potentially) pregnant body and "choose" against intersex. As Sparrow claims, selecting against intersex "is morally permissible," perhaps even "required" (2013: 29, 34). Rather than unimpeded choice and unproblematic reproductive freedom, PGD and the accompanying narratives cultivate the best conditions for eugenic choices. Like Holmes (2008), I defend and insist on the right of people to choose one embryo over another. Nevertheless, identifying and critiquing the eugenic ideologies that suggest using PGD to select against intersex is a benevolent and entirely free choice is vital if we are invested in reproductive freedom and resisting discrimination and inequitable power relations. Choice and coercion, freedom and discriminatory cultural imperatives are coextensive.

#### Session 6: Thursday 14:00–15:30

Margit Anne Petersen & Dorthe Brogård Kristensen (University of Southern Denmark), *Potential selves: Ethnographies of technologies of optimization and values for the future*

Contemporary society is witnessing a surge of new technologies to optimize mental and bodily well-being and capability such as medical enhancements, cosmetic surgery, dietary fashions, as well as a variety of technological devices for tracking and monitoring the self (Askegaard 2002, Hogle 2005, Pickergill & Hogle 2015). Some scholars have pointed to the cultural dictum to improve one's health and well-being, and how the body in the digital age is figured as a smart machine that can be extended and enhanced if needed (Lupton 2013, Ruckenstein & Pantzar 2015). Citizens are expected to stay informed, to make the right choices for themselves with regards to exercise, diet, rest and sleep based on government guidelines and to evaluate health risks as a strategy of "making the most" and to "optimize all aspect of life (Henderson and Peterson 2002). Technologies are clearly envisioned to realize a future 'potential' for the individual, yet this potential is not a neutral term designating a known property; it implies and enforces directionality (Høyer & Taussig 2013). Technologies such as these have previously been framed either in terms of empowerment and self-esteem enhancement (Swan 2012) or seen problematically as tied up with issues of surveillance and control (Reigeluth 2014; French and Schmidt 2013). Other studies have shown how people use technologies in everyday life (Lomborg and Hansen 2015, Lupton 2012, 213, 2014; Petersen Ruckenstein 2014, Ruckenstein

and Pantzar 2015, Nafus and Sherman 2014, Petersen 2015, Sharon & Zandbergen 2016). There are only few studies who actually analyze how different types of technologies are utilized to “optimize” the self, less how those using them actually perceive and articulate the processes and ‘results’ of optimizing. On this backdrop the aim of this paper is to explore technologies of optimization and their use in imagining, experimenting with and realizing potentialities of the self. To this end we ethnographically explore optimization of the self in two different empirical settings, e.g. the use of pharmaceuticals and practices of self-tracking (Ruckenstein 2014; Lupton 2014). More specifically the focus in the paper is on the human/technology assemblage, and how it is experienced and practiced by young adults. What are the notions of the self that drive this exploration? What happens when people set out on this kind of explorative journey? What kinds of practices does the journey consist of and what kinds of outcomes does it yield? In line with Pickergill & Hogle (2015) and Verbeek (2008, 2011) we focus on how object ontologies (nature of technology) and subjective properties (authenticity, personhood etc) are co-produced. and show how the notion of optimizing is associated with feelings and experiences of the human bodily self, restrictions connected to the use of technology, as well as a (re)negotiation of human values.

Samantha Gottlieb (Independent Scholar): *The sensed female body*

“What is nirvana for self-trackers is hell for diabetics,” argues one STS scholar (Mialet 2015, personal communication). A group of type 1 diabetes (T1D) open source hackers (OS/H) patient advocates perceive data as liberation, building algorithms to automate diabetes tracking and troubling standards of aggregate population-level data; they simultaneously present as compliant patients and as disruptive citizens, challenging standards for healthcare management and legal and regulatory processes. The n=1 is and has always been the focus of their own longitudinal self-care. Yet this reclamation of data as a form of self-empowerment and advocacy can obscure gendered, racial, and class forms of privilege that citizen science may always have to navigate. Through research with members of T1D OS/H community, I explore how they draw on the intersections of health, regulatory, legal, and software discourses, which often refute and contradict each other. In particular, I consider visual representations of T1D bodies on social and digital media. The vaunted commercial medical devices that may permit the artificial pancreas to (purportedly) soon become a reality has led to a proliferation of images of bodies wearing sensors to demonstrate size and portability of diabetes technology. These images show white, exposed female midriffs (denoted by a curved waist and hairless abdomen). What makes the female body the perfect icon of sensor technology? How do the images of these female bodies contrast with the members of the hacking communities? And whose bodies get effaced from the access to care, meant to directly challenge medical and commercial authorities?

Amelia Fiske, Alena Buyx & Barbara Prainsack (Institut für Experimentelle Medizin, UKSH): *Examining representation, access, and difference in biomedical citizen science*

Citizen science initiatives often claim to democratize health and biomedicine, through the empowerment of lay people to inform and direct their own medical care (e.g., practices such as gut sampling, self-tracking, or genetic research). The use of citizen science in biomedicine has been argued to produce ‘better’ results than conventional science either because the results are produced faster, because they lead to more socially robust applications, or because they solve previously unresolved questions. However, as scholars have noted, such initiatives are utilized by a relatively select group of people, favoring those who are white/western, English-speaking, highly educated, and often already computer savvy and scientifically literate. This paper raises concerns regarding representation, access, and difference that are particular to the incorporation of citizen science in biomedical research. Specifically, we ask how the rise of data collection on and by the self may intersect with existing inequalities and hierarchies of knowledge production in the biomedical sciences. Drawing on our analysis of citizen science initiatives, we push for a proactive approach to representation;

that is, if citizen science claims to bring opportunities by 'opening' science and medicine in new ways, it must also be accountable to a range of publics. This requires a critical examination of how changing forms of participation (e.g., self-monitoring, data and sample contributions, online communities, citizen-directed research) in the biotechnological landscape are inflected with questions of race, class, gender, literacy, as well as historic exclusions in the field of health.

Keynote 2: Thursday 16:00-17:30

Heidi Tikka (Aalto University): *Body-Sensor Co-performances: Working with Interactive Technologies for New Media Art*

Over the last few decades I have produced installations and artifacts, which act responsively towards their audience. In my presentation I will outline in detail, how these human-machine encounters are conceived by implementing a number of relatively simple, low-tech interactive technologies. My focus will be on the experimental work on sensors monitoring different embodied actions and bodily processes. What happens in these events, in which bodies are expected to make contact with sensors? What kinds of transformations take place? I will suggest that each of these technical configurations will frame the body in its particular ways. That is, the bodies enacted by and within these arrangements must be understood relationally, as performances in which embodied dynamic materialities and the mechanisms of measuring interact. The installations, however, play in other registers too. How to think of this complexity, and how to make imaginative alignments, in which the body-sensor co-performances resonate productively with the visual and the psychical dimensions of the work?

Keynote 3: Friday 9:30-11:00

Deborah Lupton (University of Canberra): *The Vital Capacities of Digitised Female Embodiment*

In this presentation, I will draw on new materialist perspectives to consider the vital capacities that are generated when women use digital technologies to monitor and discipline their bodies. I will begin with outlining the affordances of the apps, other software and devices that are available to and marketed specifically at women for these purposes. I will then use material from several of my research projects involving Australian women talking about their experiences with these technologies. These include a study involving focus groups with women who are pregnant or in the early stages of parenting, another project using telephone interviews with a broad range of women around Australia, and a third study involving both face-to-face interviews and focus groups with women living in Canberra. These research materials will be used to discuss the assemblages of humans-devices-software-data that are configured when women engage with these technologies and the range of vital capacities that emerge from these assemblages.

Roundtable: Friday 11:30-13:00

Harley Bergroth, Susanna Lindberg, Chris Till, Ayo Wahlberg