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## The "Me" in the "We" Anthropological Engagements with Personalized Medicine

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# The "Me" in the "We"

## Anthropological Engagements with Personalized Medicine

Mette N. Svendsen

No one can doubt the current relevance of personalized medicine in Danish society. "The state will steal your DNA"<sup>1</sup> and "Critique: DNA project is high risk"<sup>2</sup> are but two catchy newspaper headlines from a heated public debate about the planned state-run national genome bank in Denmark, Nationalt Genom Center. What has spurred discussion is the government's suggested organizational and ethical framework for collecting, banking, and using genomes from the Danish people as part of its realization of personalized medicine in Danish health care. The framing of "stealing" and the articulation of this project as "high risk" points to the discussion's central issue of how to treat and administer genomes as concomitantly part of the "me" of the person and the "we" of the welfare state. Anthropology has a lot to offer in understanding the intertwining of the person and the collectivity. But before I discuss what anthropology can bring to personalized medicine and this question, let me begin with what anthropology is.

The word "anthropology" tells the basic story about what anthropology is: the study (logia) of the human (anthropos). Among the many disciplines that study the human, anthropology addresses the human as a social being – as a "me" in the "we" of sociality and culture. The key question of anthropology is what it means to be human (Geertz 1973). This question highlights the human as a meaning-making person with a capacity for reflection, language and moral virtues.

Medical anthropology is one of the most highly developed areas

<sup>1</sup>"Staten vil stjæle din DNA", Two page article in EkstraBladet, December 2, 2017.

<sup>2</sup>"Kritik: DNA-projekt er højrisikabelt", frontpage article in Politiken February 26, 2018.

of anthropology. It holds a longstanding interest in how birth, health, suffering, and death are understood, experienced and theorized through time and in different cultural settings (Innhorn & Wentzell 2012, 2). Medical anthropology interrogates how the human body is related to larger societal and global issues. More than any other discipline of anthropology, medical anthropology has developed through interdisciplinary dialogues; in particular with Science and Technology Studies, History, Global Health, Mental Health, Genetics and Reproductive Health, and not least Public Health.

As I enter a professorship in medical anthropology, I stand on a rich platform of anthropological approaches to the human and continue the interdisciplinary conversations of this field. Based in the Department of Public Health at the forefront of the integrated study of medicine, health, and society, I am in a privileged position to simultaneously bring anthropology into public health and to make formative contributions to the field of medical anthropology.

Like all good fairytales, this lecture is structured in three parts that follow the temporal categories of past, present and future: What has brought me here? How do I approach the "me" and the "we" of personalized medicine? Where am I heading?

### Liminal lives in the Danish welfare state

For the last fifteen years, my research has been guided by an interest in how new medical science and technology transform the way we understand ourselves as individuals, in relationships, and as a species. Based on participant-observation in Danish health care and laboratory science, I have investigated how IVF embryos are donated to stem cell research, how life-and-death-decisions are made when extremely premature infants are at the margins of life, how elderly people with late-stage dementia are cared for when they lose memory, language and rational autonomy, and how piglets are modeled as stand-ins for humans in experimental science. These beings are at the edge of humanity. They are what Susan Squire names "liminal lives" (Squire

2003). Liminality means "being at the threshold" between one space and another. It is the ambiguous zone in between categories of the normal (Turner 1969). We enter the liminal zone in cultural rituals that mark a transition from one stage to another – baptisms, weddings, funerals, graduations, or inaugurations like today. Liminal zones expose dominant cultural values and make it possible to reflect upon them and question them. Anthropology has a long tradition of studying liminality as a space of potentiality, experiment and cultural change (e.g. Kapferer 1991).<sup>3</sup> In STS and feminist studies, liminality has been taken up in discussions of post-humanism (e.g. Braidotti 2013).

IVF embryos, research piglets, premature infants, and people with dementia are liminal lives in the sense of being in between life and death. They are brought into existence or are maintained in life through medical science, medical techniques, and skilled care. Liminal lives raise questions about the boundaries of the human person. What is the status of the 'person' in the embryo, the prematurely born infant, the person with dementia, and the near-human research animal? How do we conceive our responsibilities towards these beings? How do we negotiate their value of life? What is the nature of their suffering? These are pressing questions for health professionals, researchers, animal technicians, patients and relatives, and legislators. To answer them, biomedical science must be placed in its social and cultural context. This is precisely the work of anthropology.

Anthropology provides a rich platform for investigating questions about the human person.<sup>4</sup> One of the fathers of anthropology, Marcel Mauss, saw personhood as a collective activity (Mauss 1985). He described personhood as the social masks that the idea of the self takes on in different societies. Later, the work of Meyer Fortes in the 1940s (1945, 1987) and Victor Turner in the 1960s (1967) conveyed how such social masks were

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<sup>3</sup> My own interest in liminality in relation to health and illness was stimulated already as an undergraduate student by professor Susan Whyte introduced medical anthropology into Danish anthropology and by associate professor Vibeke Steffen who later became an invaluable supervisor for me during my PhD studies.

<sup>4</sup> The following two paragraphs draw on Svendsen et al. 2018.

reflected in rituals and cosmological understandings of beginnings and endings of life bringing Fortes to argue that personhood "is intrinsic to the very structure of human society" (1987, 253). More recently, anthropologists and social scientists have examined the biopolitical forces, medical technologies, legislation and lived experiences, which shape the very becoming or erosion of personhood in liminal persons. In particular, these forces and lived experiences have been brought into focus in studies of reproductive selection (Franklin 2007; Koch 2014; Gammeltoft 2014; Morgan 2009; Rapp 1999; Taylor 2008a), organ transplantation (Sharp 2013; Lock 2001), disability (Wool 2015), death, and dying (Kaufman 2005, 2015; Lock 2001; Taylor 2008b; Verdery 1999). In many ways, I stand on the shoulders of these scholars and am fortunate indeed to know many of them and to have developed my scholarship through conversations with them. Even as the old and the new works take personhood in different directions, they all share and contribute to the strong interest in the core anthropological question of what it means to be human.

Clinical and laboratory practices around IVF embryos, research animals, premature infants, and people with dementia provide a great opportunity for investigating the human condition and its margins. But to question the meanings of these life-forms would trivialize what was right in front of me and my team: the work caregivers put into sustaining these beings. This work alerted me not so much to what it means to be human, but to what it takes to be a human person, as a continuous effort of becoming. The fact that the embryo, the preterm infant, the person with dementia, or the piglet are not able to speak for themselves unmoors them from the narrating meaning-making being we instantly recognize as human. Embryos in white plastic tubes known as straws, grunting pigs in boxes, infants the size of my hand in incubators, and people with dementia without speech and motor function provided me with the opportunity to derail the human person as the unquestionable starting point of anthropology. Becoming intimate with these beings, I could ask how their human personhood is created, maintained, or dissolved in specific socio-moral-material practices (Svendsen and Koch 2008; Svendsen 2011; Svendsen et al. 2017).

In particular, my studies of research piglets in biomedical experiments (Svendsen and Koch 2013), and of premature infants in neonatal intensive care treatment (Navne and Svendsen 2017) have demonstrated the social, spatial and temporal imaginaries at stake in constituting the human person and negotiating the value of life. Juxtaposing practices in the pig lab with practices in the neonatal intensive care unit shed light on why some lives come to matter as qualified biographical lives – lives we recognize as persons – and others come to matter as non-personal biological life (Svendsen 2015).<sup>5</sup> My research showed that the infant was turned into biographical life by being situated in a family, connected to a home and imagined as someone who would be able to eat, talk, move, and walk independently, and by being provided with an open future (Svendsen et al. 2018). And the comparison revealed practices of drawing the piglet into dimensions of biological life by detaching it from the mother sow. Socially, the research piglet did not have a pig family, but was put in relations to the scientists and the infants it modeled in the clinic. Spatially, the piglet was totally integrated with the scientific institution (the university) and not imagined as eventually coming to move around freely. Temporally, the piglet was enrolled in the time of the research protocol, which provided it with a fixed kill day, not an open future as was the case for the infants in the clinic. Surprisingly, my comparisons also demonstrated the blurred states, as well as the slippage between life as biography and life as biology in both the neonatal intensive care unit and the pig lab. Research animals could gain biography in daily care practices, and human infants could slip into biological lives when the hoped-for open-ended futures could not be achieved (Svendsen 2015).

In going back and forth between the pig laboratory and the neonatal intensive care unit I developed the methodology "thickness by comparison" (Svendsen et al 2017; 2018). In their work anthropologists aim for

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<sup>5</sup>This work was made possible through my many years of collaboration with Professor of Clinical and Experimental Nutrition Per Sangild and his group at the veterinary campus of the Faculty of Health Sciences at the University of Copenhagen, and also through my collaboration with the Neonatal Intensive Care Unit at Rigshospitalet.

thick descriptions (Geertz 1973). In contrast to factual accounts, thick descriptions are contextualized, rich and interpretive accounts of the meaning structures that make up a culture. My methodology of thickness by comparison aims for thick descriptions by bringing different sites into the same analysis. This methodology treats one empirical site as a "prism" for the other site and lets the comparison of different sites and care practices reveal the different and interconnected edges – the margins – of the human. Comparison is at the heart of anthropology and through time anthropologists have compared kinship, sociality, economy, religious practices across cultures (e.g. Bath 1969; Mead 1977; Strathern 1991). But whereas classic comparisons in anthropology have moved across geographical distances, thickness by comparison travels across categories of human and animal, newborn and old, and – as I will show below – the digital and the corporeal – within the same society. This methodology is simultaneously "multi-categorical", "multi-sited" and "multi-species".

In my current project on the worth of life, called LifeWorth,<sup>6</sup> Laura Emdal Navne, Iben Mundbjerg Gjødsbøl, Mie Seest Dam and I have moved between the neonatal intensive care unit, the dementia nursing home, and the animal laboratory. We realized that it may be that premature infants, people with dementia, and research piglets are at the margins of life. But they are at the same time at the center of the welfare state (Navne and Svendsen 2017; Dam et al. 2017; Gjødsbøl, Koch and Svendsen 2018). Their existence, their care, and their housing depend on welfare state regulations (policies) and daily care practices in welfare state institutions. And very profoundly, the clinicians in the clinic, the caregivers in the nursing home, and the animal researchers and technicians in the pig lab identified with the welfare state. In daily care and in life-and-death decision-making these professionals reflected on ethics, and their reflections were not only centered on what they personally considered good care, but on what they saw as the right kind of care within a welfare state (Svendsen et al. 2018).

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<sup>6</sup>"A Life Worth Living: Negotiating Worthiness in Human and Animal" (Sapere Aude grant 12-133657) funded by the Danish Council for Independent Research.

Care for liminal lives in the welfare state reveals the many ways in which the person, the "me", comes into this world through the collective "we"s of families, professional collectivities, and welfare state institutions. These insights about what it takes to be a human person provide a unique entry into my newly initiated Semper Ardens project "Personalized Medicine in the Welfare State" (MeInWe) generously funded by the Carlsberg Foundation. MeInWe asks: How is the "me" understood and established when genomic data are generated, exchanged, and interpreted in Danish health care? Which "we"s are shaped and constituted in drawing boundaries around the "me"?  
Now, I enter the present.

## The "Me" and the "We" in personalized medicine

What is personalized medicine? Personalized medicine is an expanding field of strategies for tailoring diagnosis, treatment, prevention and research to the individual or more often to particular groups of individuals. Among the different technologies included in the vision of personalized medicine, gene technologies are key. Sequencing a human genome – the sum of a person's DNA – and combining this knowledge with clinical data, information about lifestyle, diet, and the environment is at the center of today's visions of personalization (Tutton 2014). Personalized medicine accelerates in institutional collaborations that cut across private and public institutions, profit and non-profit set-ups (Prainsack 2017; Reardon 2017). With corporations like Google, Facebook and Amazon entering the field of health, very soon public tax-financed health-care may no longer be the only framework of health services in Europe. Big corporations have collected and stored enormous amounts of data about each of us.

As recent public controversies have revealed, our lives are not only being enhanced by these corporations, but also possibly being transformed into their profitable product.<sup>7</sup>

If we zoom in on our local situation, the Danish Regions launched their action plan for personalized medicine in July 2015 (Danish Regions 2015), and subsequently the Danish government launched their strategy of personalized medicine in December 2016 (Ministry of Health 2016). This strategy allocates 100 million DKK to the development of personalized medicine and to the establishment of a new institution: The National Genome Center. The vision for this center is to establish a common national technological infrastructure for banking and using genomic information and other health information about citizens – with the aim of improving treatment for patients. According to the political strategies, collaborations with private companies are key to reaching this aim. Consequently, the realization of personalized medicine for the individual "me" relies on the "we" of the welfare state (investing in the field), the "we" of life science industry (to enter public-private partnerships), the "we"s of the National Genome Center and other data archives, and the "we" of public trust (people willingly banking genomic and other kinds of information).

I will now invite you into some of my present thoughts on personalized medicine in Denmark and briefly introduce three analytical figures that may open up an avenue for exploring urgent questions about how genomics shapes the "me" and the "we" and their interconnection.

The first figure is the "underground common", a concept from the anthropologist Anna Tsing (2015, 274). In my earlier research when I moved between the animal facility housing piglets and the neonatal intensive care unit treating babies, I came to see animal laboratories as

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<sup>7</sup>The Facebook-Cambridge Analytica scandal (March 2018) is an example of free services for users (free access to Facebook) being turned into profitable data for the companies offering services (e.g. Facebook and the firms with which Facebook collaborates). Based on such data, companies may develop behavioral algorithmic models and use these models to micro-target users or voters with ads matching their psychological traits. While the Cambridge Analytica scandal made Facebook announce the destruction of the raw data used to develop the models, the models themselves continue to be used and sold and potentially shape electorates (Metcalf 2018).

an extension of the human clinic. Care for human patients in the clinic extends into animal facilities in which the life, suffering, and death of laboratory animals are deeply implicated in creating healthy lives for humans (Haraway 2008). Research animals are truly "underground" as they are not mentioned in clinical practices and surprisingly often they live in basements (Bjørkdahl and Druglitrø 2016). Research animals also constitute a kind of "common" as their lives, suffering, and death are turned into a resource for all of us.

Like research animals, collected genomic data from many many individuals make up a shared resource – a virtual "underground common" essential to tailoring medicine to the one individual. This is so because personalized medicine aims for a data-intensive characterization of the one individual by comparing data from this one individual with data points from thousands of other individuals. Other people's genomes constitute a necessary precondition for interpreting one individual's genetic profile, and consequently, reciprocity between individual and collective is at the heart of generating and interpreting genomic data. And interpretation is key (Reardon 2017). The clinical implications of genetic variants are far from clear. Consequently, the interpretations of the "personal" genetic profile presuppose a relationship between one person and other individuals in the data archive (and the clinicians/geneticists who interpret the data). In this way, every characterization of the individual "me", bears the trace of the "we" of the underground common. The concept of the "underground common" directs attention to the interconnectedness of the individual in health care and the common resource in the data archive. It may help us answer pressing questions about how the contents of the underground common (the digital genomes) determine what can be known and who can be cared for in the clinic (cf. Reardon 2017, 161).

In personalized medicine, the entanglement between person and data – between citizens and their genomes in the underground common – are widely recognized. The housing, social life, and future of genomic

data are continuously discussed and cared about in public debates.<sup>8</sup> The current Danish debate about the National Genome Center has raised questions such as: How should citizens give their consent to have their genomic data stored in the National Genome Center? What is the value of genomic data and how will it be used? With whom will data be exchanged? Despite the different views raised on how to organize the storing, use, and exchange of genomic data, everyone understands genomic data as closely connected to the person. Digital genomes are not seen as neutral or innocent entities. They are conceived of as potent representations or extensions of individual patients. This is not only the case in the public debate, but also in the clinic. When oncologists, cardiologists and clinical geneticists interpret genomic data and draw on such data in personalizing treatment, genomic information is treated as an extension and a signifier of that patient.

As my colleague, Klaus Høyer has shown in his ground-breaking research on exchangeable body parts, banking data about individual persons raises fundamental questions about the relationship between tissue, data and person (Høyer 2013). Inspired by Høyer's work, I am interested in the many different digital and corporeal manifestations of the "me" and their interrelationships, which come into the world with personalized medicine. In what form and to what extent does "the person" remain in the tissue and the data in the archive? How do different forms of data relate to each other and to the embodied subject?

To answer these questions about the different manifestations of the "me" in personalized medicine, the concept of substitution may be helpful. Substitution is my second analytical figure. Substitution means "replacement". It implies a notion of an original and its stand-in, which

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<sup>8</sup> Examples of headlines from Danish newspapers between November 2017 and March 2018: "Take care: The state will take your DNA" [Pas på: Staten vil tage dit dna] Politiken November 2, 2017; Stop Scare Campaign against Genome Centre" [Stop skræmmekampagne mod et genomcenter], Politiken November 22, 2017; Culture of Worry" [Bekymringskultur], Weekendavisen December 1, 2017; "the State will steal your DNA", Ekstra Bladet December 2, 2017; "Critique: DNA project is high risk" [Kritik: DNA-projekt er højrisikabelt], Politiken February 26, 2018; "Is it sensible to collect and store gene material from the Danes in a national DNA Bank?" [Er det fornuftigt at samle og opbevare genmateriale i en national dna-bank?], Kristeligt Dagblad March 9, 2018.

is "below" or possibly "lesser" than the original. The concept thereby reflects a Euro-American conception of the autonomous person as unique and authentic, in contrast to its replacement (Franklin 2007, 203-204). For example, piglets in the lab and other research animals come into this world as substitutes for human patients or human biology (Sharp 2014; Thompson 2013).

In the field of personalized medicine, the many investments into genomics seek to create and mobilize precise and convincing digital substitutes.<sup>9</sup> Genomic data and other kinds of health information are treated as artefacts that by being integrated and connected make up digital substitutes for human embodied subjects. When unmoored from the human body, digital substitutes may circulate in research networks, get a life of their own and survive the person in flesh and blood. We cannot any longer assume that digital substitutes die when the subject dies. The social life of digital substitutes illuminates their "tethering potential" (Hinterberger and Porter 2015, 362) in the sense that they may be attached to both transnational research and nation states (Tupasela 2017) and acquire value through circulation.

In a Danish context, citizens live their lives in and out of state-financed institutions – day care, schools, hospitals, nursing homes – which most people see as trustworthy partners as well as self-evident platforms from where to be born, mature and acquire knowledge and skills, contribute to society, receive care, and eventually end their lives (Hansen 2002; Jensen 2016; Jenkins 2011). In Denmark, we might say, it is through state institutions that one gains personhood and becomes a free human being. As the Swedish historian Lars Trägårdh argues, in Scandinavia, citizens do not distinguish strongly between state, society, and the people, but see organic links between them (Trägårdh 2002).

<sup>9</sup>Social science studies of digitalization and surveillance have used the notion of the data double to explore the ways in which disembodied accumulation of data come to stand in for the individual (Elmer 2003; Haggerty and Ericson 2000, Lyon 2007). These studies see the embodied subject as "the real" and the disembodied data as its faked representative. While I take inspiration from these studies, my concept of substitution does not by default see the fleshy self as the original, but seeks to understand the various material manifestations of the person and to follow the processes through which something or someone is configured as original or substitute (cf. Grew and Svendsen 2017).

People have trust in public institutions and most people see tax financed health care as the best way of securing a fair system and good health for everyone based on principles of solidarity. As Danes, we tend to get more upset if the health professional in front of us is not up-to-date about our medical record than if the health professional has access to our data without our explicit consent.

But there are questions. In order to realize the health promises of personalized medicine, public-private partnerships within and beyond the welfare state are key. What happens to digital genomes in these public-private partnerships? Will citizens continue to experience organic links between themselves, society and the state and thus trust the state's care for their digital substitutes? The current debate about the genome center illuminates that digital substitutes in state institutions have great potentials, but also that they create an uneasiness that is hard to ignore – even for people who are proponents of the National Genome Center. How should we understand this uneasiness?

The concept of substitution entails a superiority of the original (the substitute is second, it comes after). What happens if digital substitutes do not respect this hierarchy? Utilizing the concept of substitution, the uneasiness that attaches to banked genomes is related to the fear that digital substitutes may leave the control of the original, or the "first" (meaning the embodied citizen). This is the fear that digital substitutes may get a life on their own, end up in corporations beyond the control of the original (the citizen) and potentially harm the citizen. In other words, digital substitutes contest our notion of originality, which is so embedded in our legal principles of human rights and protection of the autonomous individual. And possibly, digital substitutes in public-private partnerships also contest organic relations between state, society and people. In the context of personalized medicine and the current discussion in Denmark about the "high riskness" of the National Genome Center (cf. Politiken), the concept of substitution illuminates pressing questions about the tensions, ambiguities, and power relations involved in creating and interpreting genomic data as part of the person and part of institutions within and beyond the welfare

state. Substitution directs analytical attention to representations that do not merely passively reflect or describe the person, but also have important material, social, legal, and scientific consequences in the world. Substitution will help us explore and discuss who and what can stand in for whom and how trust in welfare state institutions can be maintained in the context of digital genomes.

To sum up, what we see is that genomes are used and conceptualized as both substitutes for persons and as an underground common that can improve public health and boost life science industry to the benefit of society. Genomes are treated as having a potential not only for manifesting personhood, but also for demonstrating and safeguarding welfare statehood. This observation takes me to my third analytical figure: the welfare state metabolism, but first a little bit of background.

The notion of citizens' genomes as resources for the welfare state collectivity grows out of the existing politics of life in the welfare state. First, Danish health care has a long tradition for comprehensive health registries that can easily be accessed by researchers. Second, Denmark has a long tradition for conceptualizing the lives of citizens as resources for society. In public discussions of the welfare state and its redistributive policies, the work of citizens and the businesses run in the welfare state are depicted as the life-sustaining fuel of society: tax income and the activities of citizens are to be converted to welfare services (schools, hospitals, infrastructure etc.) and create prosperous and fulfilling lives for citizens. Similarly, the political strategies for personalized medicine conceptualize genomes as a fuel, a natural resource, for society.<sup>10</sup> These political strategies and discussions about genomes as natural resources depict the welfare state collectivity as a metabolism: an organism that converts matter to sustain itself and live. To conceptualize society as an organism has a long history. Early sociological functionalist studies saw modern society as an organism

<sup>10</sup> The short version of Danish Region's political strategy on personalized medicine (Danske Regioner 2015) begins the document by presenting the unique health registries in Denmark as basis for improving public health and ends the document by a strategy for creating economic growth by boosting Danish life science. The argument is that the Danish situation creates a unique possibility for the development of personalized medicine.

based on division of labor equal to internal organs performing different functions to uphold the body from within (see Landecker 2013 for an exploration of the relationship between theories of the metabolism as part of historical times). However, the welfare state metabolism that appears in current discussions about personalized medicine is not similar to this old notion of society as a self-contained entity. It is, rather, a metabolism with porous boundaries to researchers, biobanks, data flows and life science industry outside the welfare state.<sup>11</sup>

My third figure, the figure of the welfare state metabolism, directs attention to how the welfare collectivity gains its shape from what enters, leaves, and becomes transformed in the welfare state. From this perspective we may ask: which digital substitutes are let into the welfare state metabolism, to which research collaborations and corporations do they travel, and through which passages, if at all, do they transform into health and wealth?

My methodology of thickness by comparison has demonstrated that liminal lives are at the heart of the welfare state and central to its metabolism. Liminal lives expose how the welfare state regulates who belongs in it – that is, who participates in the metabolism of the collectivity. Genomes may be seen as liminal lives in between person and thing. Why not widen the perspective and compare the social and legal regulation of genomes with the administration of other liminal lives? Would such a comparative perspective crack open how welfare state policies and practices encourage certain incorporations, exchanges, absorptions, and excretions more than others? How welfare state policies and practices articulate some liminal lives as the life-giving powers and others as the life-draining powers of the welfare state? Would it be possible to compare the administration of genomes with the administration of fetuses and infants at the margins of life, or of people

<sup>11</sup> Recent social science scholarship concerned with post-industrial theories of metabolism depict a shift in the biological sciences from understanding metabolism as a factory (converting food to energy) to conceptualizing metabolism as a regulatory zone (responding to environmental information and connecting environments and organisms) (Solomon 2016; Law & Mol 2008; Landecker 2011; Landecker 2013, Wilson 2015). These studies have been very inspirational for me in conceptualizing the welfare state as a metabolism.

with dementia, or of migrants entering the country, or of research animals and animal genomes? Such a comparison has the potential to illuminate what it takes to be a person in the welfare collectivity, and what it takes to sustain this collectivity. But I am getting ahead of myself. Let's look at the near future.

## The moral agency of human actors

My suggested analytical shift from what it means to what it takes to be a human person, emphasizes that the human person is not an a priori entity. The human person is shaped in social-moral-material practices and in relation to historically specific understandings of personhood, statehood, social and individual obligations and rights. And the human person is also a result of placing bodies, tissue samples and data in specific social, spatial, and temporal constellations.

Is it then the case that my analytical shift from "what it means" to "what it takes" moves me away from traditional notions of human subjectivity? No, this is not the case. I keep a sensitivity towards enactments of the human person (as I have emphasized so far) and towards the moral agency of the human actors at the center of these technological and scientific practices. I wish to investigate how professionals', patients' and citizens' daily engagement with genomes raise questions about the 'good' – about what counts as a good life and what counts as the common good. I do this in at least two ways. First, I ask what is ethically at stake for the great variety of people involved in personalized medicine. I keep a stubborn (pigheaded!) focus on how people reflect, question, hope and act. This is not simply a question of adding new empirical data to the study of a new technological field. It is a question of framing and perspective. My insistence on moral agency is a matter of investigating the "me" and the "we" as ethical and relational matters (Kuan and Grøn 2017; Lambek 2015; Mattingly 2013) when researchers and health professionals care for research animals; enter collaborations with public and private partners; sequence DNA; grow cells; bank data; analyze tissue samples and data; make decisions

about what information is significant enough to be pursued and acted upon; draw family trees and sit in front of terminally ill cancer patients who may have their lives extended with personalized medicine cures.

Second, the other way I engage the moral agency of human actors is through interdisciplinary dialogues. By collaborating with clinicians, researchers, animal technicians, data curators, and administrators I continue the interdisciplinary conversations that have always been so essential to medical anthropology and indeed to public health. My concept of "critically engaged research" (2008) has helped me address the dual roles I and my biomedical colleagues have to navigate when collaborating across social science, basic science, and clinical practices. As an anthropologist, I am inclined to critically address the dominating assumptions of the field I'm studying and avoid the acceptance of immediate, commonsense understandings. My critical training urges me to investigate what common sense understandings produce, but not to take them for granted. This criticality provides a possibility for always writing a narrative that is different from the ones being told in the science fields themselves. But as a colleague of my biomedical researchers I wish to engage the challenges and concerns they face. This is an engagement that is grounded in direct interactions and solidary relationships with my colleagues in the science fields.

Critically engaged scholarship is rarely a smooth experience. It is not simply a matter of ferrying knowledge across from social science to medical science. Moving across disciplinary boundaries involves discussions about what counts as knowledge, and it often implies translation between different disciplinary "species". It can be a very unsettling experience for the biomedical researcher to be the object of the gaze of the anthropologist, and it can be a very unsettling experience for the anthropologist to conduct critical research while entering solidary relationships with one's colleagues and hosts in the biomedical field. Nevertheless, in my collaborative relations a mutual willingness to engage in the perspectives of one another has not only survived, but also resulted in co-authorships that in themselves represent an action of translation (Dam et al. 2017; 2018). On a day-to-day basis

these collaborations have revealed to me the intertwined nature of the "me" and the "we". I have become a "me" – a scholar of medicine, health, and society – through my engagement and commitment to the "we" of interdisciplinary dialogues and interdisciplinary collaborations in the science fields and in public health.

In entering the field of personalized medicine, this critical engagement is taken to a new level. By collaborating with central actors in the fields of personalized medicine, my team and I will create an ethical laboratory for searching out good ways of integrating personalized medicine into the Danish welfare state. We will invite into the ethical lab clinicians, researchers, industry representatives, patients and administrators to discuss the ethical questions they encounter in relation to personalized medicine. The ethical laboratory is a space for reflection and discussion of ways of doing and giving shape to personalized medicine. With the ethical lab, I engage the translation between genomics and society and continue the strong interdisciplinary conversations of medical anthropology and indeed of public health. The fundamental idea of the ethical laboratory is to ask anew how the "me" and the "we" are intertwined with the ethical question of "what is the good life"; as this question appears in situated everyday practices inside and outside of clinical and laboratory settings.

MeInWe is a unique project. The uniqueness of the project is not only due to its size, its generous funding from the Carlsberg Foundation, and the elite scholars who are part of it – although all of this is very important. The uniqueness of the project also lies in our collaborative relations. MeInWe employs a collaborative mode of doing research that takes inspiration from thickness by comparison to bring about critical and analytically surprising insights about personalized medicine. In MeInWe, each ethnographic or text-defined site operates as a prism for gaining insights into another site. We do this by carrying out empirical research together and by letting our meetings establish what Kirksey and Helmreich call "parasitic encounters" (2010, 558). These encounters are parasitic because each site comes into being and lives on and gains life from another site. We use the differences between

our disciplines and sites as a source of new questions about what the person becomes in the context of personalized medicine.

This collaborative approach literally embodies the "me"-scholar in the "we"-team and takes seriously the basic and fundamental insight from anthropology that life is lived relationally and that the human person comes into being through relations. The "me" always relies on the "we".

## Thank you

The "me" in the "we" is indeed my personal story in academia. Unlike many anthropologists who work as soloists, through my whole career I have been in the fortunate position to work in groups and to foster my own groups. As I end this talk, I wish to express my deep and sincere THANK YOU to my LifeWorth-team and my MeInWe-team and to Professor Lene Koch who has been my mentor, colleague and friend from the beginning of my PhD studies to the present. Lene Koch has handed over to me the greatest gift of all: the Semper Ardens ("always burning") approach to life that fosters exceptional research. She has taught me passionate thinking.

## Biographic Note

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