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POSITION PIECE

‘Health Data Saves Lives’, But Which Lives?

The Non-Imagination of Ecological Peril in Precision Medicine

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Abstract

Precision medicine is a field of future promise. Its imaginary is that ‘health data saves lives’. But which lives and at what costs? In this position piece, we direct attention to how non-imagination (Prainsack 2022) operates in the field of precision medicine. We argue that central actors in the field, along with social scientists researching it, non-imagine the relevance of environmental collapse to the pursuit of precision medicine, despite its huge energy consumption and focus on prolonging human lives in places that contribute the most to climate change. This non-imagination raises questions about how we as medical anthropologists approach and theorise the ‘life politics’ at the centre of anthropological studies of the life sciences. In light of the current ecological peril, we advocate for extending the discipline’s focus from the governance of life in politics, labs, and clinics to the governance of ‘earth-life’.

Keywords

Precision Medicine, Sustainability, Non-imagination, Common Good, Value of Life.

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On a grey January morning in 2023, we enter Parliament in Copenhagen, Denmark, to participate in a hearing on the future of precision medicine, organised by the Danish Association of the Pharmaceutical Industry. We walk through a beautiful and spacious hall, which often serves as the backdrop for news reports and important political announcements. Since 2018, we have followed the implementation of the Danish precision medicine strategy in the research project *MeInWe* led by Mette N. Svendsen.[1] Today’s hearing is part of our fieldwork activities covering observations in political, clinical and laboratory settings, and interviews with central stakeholders. As the time approaches 9 a.m., the hall of about 80 seats slowly fills. We recognise leading scientists, bioinformaticians, and clinicians, along with directors of biobanks, government institutions, and representatives from the pharmaceutical industry. The three-hour meeting is scheduled to include presentations and a panel discussion with central actors in the field of precision medicine as well as a politician responsible for public healthcare.

Precision medicine is heralded as the future of biomedicine. The vision is a targeted, data-intensive approach that tailors medicine to each person’s individual genetic, environmental, behavioural, and clinical profile. In Europe, public healthcare systems and private foundations increasingly invest in realising this promise. In 2016, the Danish government launched a national strategy for precision medicine (National Strategy for Personalised Medicine 2016), which involves offering whole genome sequencing to patient groups and building an infrastructure for storing and using genomes ‘For the Benefit of Patients’ (which is the name of the strategy).[2]

As we wait for the political hearing to start, we say hello to participants from the Danish National Genome Center (DNGC), whom we know from our collaborations in the field. The DNGC is responsible for storing citizens’ genomes and combining genomic data with data from Danish registries, which collect comprehensive health, economic, and personal data on all Danes from birth to death. The combination of genomic and registry data is critical to realising the data-intensive, targeted approach to prevention, diagnosis, and treatment envisioned by proponents of precision medicine. Since the establishment of the Nordic welfare states in the 1930s, national data collection has been a routine part of the continuous evaluation and adjustment of welfare policies (Bauer 2014). Data is seen as a means for governing the common good and improving the lives of citizens by making the bureaucratic structures of the welfare state more efficient (Pinel and Svendsen 2021; Jensen and Svendsen 2022). Today, Denmark is a

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[1] MeInWe is funded by the Carlsberg Foundation. 10 social scientists have been employed in the project. See https://meinwe.ku.dk.

[2] All translations are from Danish by the authors.

digital frontrunner, and data from Danish registries and biobanks constitutes a rich and internationally renowned source for research (Hoeyer 2023; Tupasela 2021). This source is crucial to precision medicine and at the centre of the discussion at today’s hearing in Parliament.

The director of the DNGC is one of the first speakers and reports that 10,000 genomes from Danish citizens have been generated and stored in the DNGC since its opening. She introduces us to Adam, a kind-looking elderly man pictured on one of her slides. Adam had exhausted treatment options for his cancer when he entered the Phase1 Clinic in Copenhagen for an experimental treatment that targeted the genomic profile of his tumour. The treatment was successful and gave him more years with his family. ‘This is what precision medicine is about,’ she explains. ‘A better future for patients.’ She links the ‘better future’ to data, which she implores ‘need to be used. We owe patients better treatment.’ Thus, Adam comes to embody the dual vision of precision medicine: using data to both optimise individual treatment and as a resource for researchers developing new treatments.

The moral imperative to use data is also taken up by the Head of Research for Copenhagen Hospital Biobank and the Danish Blood Donor Study, comprising one of the world’s largest biobanks and genomic cohorts. She emphasises the importance of reusing ‘all the health data we already have, as well as generating new data which can help us identify new targets and precision medicine therapies.’ In large, capital letters, her slide reads: ‘Health data save lives.’ She implores the audience: ‘Why don’t we use them? I find it ethically deeply problematic that we don’t reuse data to a greater extent (. . .) [With reuse of data] we will save lives.’ With her emphasis on reuse, she advocates for loosening Danish legislation that hinders data from flowing seamlessly between research (where many omics data are generated) and the clinic, where data aims to improve care of patients. The ‘data save lives’ message also appears on the last slide of the presentation from a leading oncologist who expresses the need for establishing a large database of genomic variants of patients which will enable knowledge about the effects of targeted therapies.

While the speakers imagine data as a resource for the common good, to the anthropologists in the room, this imagination raises questions about whose good and which lives belong in the national Danish collective. At a time when we must urgently examine how human ways of living accelerate environmental crises, we were struck that ecological costs of pursuing precision medicine were absent from ethical consideration.

Non-imagined futures in precision medicine

Since Denmark started pioneering the field of precision medicine, we have heard professed the expectations of precision medicine many times. Political stakeholders, biomedical researchers, and data scientists have promised better treatments and positioned Danish biobanks and registers as a ‘gold mine’ or ‘golden egg’ that will boost life science investments and attract the pharmaceutical industry (Tupasela 2021; Hoeyer 2023; Svendsen and Navne 2023). The hearing is part of a larger landscape of political activities that shape investments and flows of money (Borup et al. 2006) and articulate sociotechnical imaginaries about how life ought, or ought not, to be lived (Jasanoff and Kim 2015). In these imaginaries, prolonging human lives is an uncontested moral and common good—a north star that justifies enormous public investment in collecting genomes, building infrastructure, and sharing health data. Ethical concerns about the pursuit of precision medicine—focusing on privacy, equity, consent, control—do not challenge this imaginary, but are continuously addressed to secure responsible conduct of a public resource. In this imaginary, the scale of the common good is the nation, and those who benefit from precision medicine are present and future Danish patients.

Listening to the presentations in the hearing, we became aware of not only the constitutive effects of imagined futures, but also how temporal ‘non-imagination’ obscures particular futures from vision (Prainsack 2022). With her concept of ‘non-imagination’ (2022), Barbara Prainsack refers to what is not imagined as relevant. ‘Non-imagination’ directs attention to the absent expectation or reflection on the future (Prainsack 2022, 24–25). In particular, the presentations made us reflect on the *absence* of ecological peril in how data saves lives. The speakers in the meeting treated the human national collectivity as a common-sense ‘we’ without thinking about this ‘we’ as a species holding existential connections to other earthlings in ecosystems. This absence is not unique to precision medicine. While there is increasing focus on sustainability in healthcare (Hodges 2017; Whitmee et al. 2015; Gaetani et al. 2024), public and political discussions focus on benefits to patients, economic costs, and scientific evidence without debating medical waste or carbon emissions. Nevertheless, we find this absence in precision medicine particularly striking. Envisioned as the future of medicine, precision medicine is a rapidly expanding, data-intensive approach gaining traction in policy, the pharmaceutical industry, and public healthcare (Tabery 2023). While data is portrayed as located in the ‘cloud’, data storage has direct material and adverse effects on the environment (Goldstein and Nost 2022, 4; Samuel, Hardcastle and Lucassen 2022). In particular, the energy required to conduct large-scale genomic and multiomic analyses or train an AI model is considerable (Jernite and Strubell 2024). To this comes the production of waste from single-use sterile implements for biopsying samples before they are turned into data. Nevertheless, in the hearing on precision medicine, none of the speakers articulated connections between, on the one hand, energy-hungry algorithms and genomic analyses that make ‘data save lives’ and, on the other, increasing temperatures which affect life conditions for both humans and nonhumans.

Which lives are saved by data? Not far from the historic hall where we sit is the Øresund, a narrow body of water connecting the Baltic Sea to the Atlantic Ocean. The Atlantic Ocean is home to cod, which have come under increasing stress due to climate change. A few weeks before the hearing, the National Oceanic and Atmospheric Administration (NOAA) reported the highest ocean heat content since the first measures in 1955. According to NOAA, ocean heat content is crucial for understanding the global climate and one of the most important indicators tracking a changing climate (National Centers for Environmental Information 2023; see also Climate Action Tracker 2025). The cod who live in the Atlantic Ocean depend on *Calanus finmarchicus*, a species of copepod, which has dispersed to cooler waters farther north, while cod offspring are transported towards warmer southern waters, thus limiting cod reproduction (Sundby 2020). Soon after the NOAA report, WWF’s *Living Planet Report 2022* was released, documenting a decline in biodiversity and genetic diversity and the degradation of ecosystems due to climate change, forestation, overexploitation of plants and animals, and pollution (WWF 2022). While the speakers and audience in the hearing might not have known about the waning cod population or the NOAA and *Living Planet* reports, they were certainly aware of the widening ecological peril. Hardly a week passes without Danish media attention to human-induced climate change, biodiversity loss, and discussions of how to reduce the flow of heat-trapping greenhouse gases.

What struck us in the hearing was the absent link between pursuing longer lives for people in the global north and exacerbating runaway climate change. This absence is not only carried by the speakers in the conference, but is an absence most citizens in the global north participate in, us included. During the hearing, we tried to address this non-imagination by asking the speakers how the planetary crisis figured into the development and operation of precision medicine. In answering our question, one speaker pointed to the importance of storing data centrally, as the energy use per datapoint is less when many data points are located on one huge server than on many smaller ones. By emphasising the resource economy, she acknowledged data’s ecological footprint and implicitly touched upon the enormous amount of infrastructure, emissions, and waste which precision medicine entails. Yet her answer sidesteps the larger tension between the urgent need to vastly *reduce* emissions to save many forms of life, and the fact that precision medicine *increases* emissions to save a tiny fraction of human lives.

The pursuit of precision medicine exemplifies the paradox of ‘self-devouring growth’ (Livingston 2019) in which practices of sustaining human life contribute to unlivable conditions on earth. After all, it is not *any* human who puts pressure on the Earth, but humans in the global north who produce the most emissions—the very human whose longevity precision medicine aims to facilitate. Yet in our diverse empirical work following the introduction of precision medicine in research (Pinel and Svendsen 2021; Gjødsbøl et al. 2024; Svendsen and Navne 2023; Dam and Green 2023), public-private collaborations (Pinel, Green and Svendsen 2023; Hillersdal and Svendsen 2022), and clinical practices (Dam et al. 2022; Gjødsbøl, Winkel and Bundgaard 2019; Navne and Svendsen 2022; Bogicevic and Svendsen 2021), we have not come across discussions of how sustainability conflicts with the imperative to prolong the lives of people whose existence is a threat to that same planet. The hearing was no exception. The uncontested life imperative underpinning the moral statements of using data to prolong patients’ lives ignores how Adam, other Danish patients, and proponents of data-intensification play a crucial role in the unfolding ecological and planetary disaster. Our point is not that Adam shouldn’t have had a few more years with his family, and we acknowledge the efforts of professionals in research, clinic, and administration who invest their lives in making the precision approach have real effects on people’s health and lifespan. What we direct attention to is how the common good, articulated through the value of a particular human life, obscures the peril of the planet.

With her concept of non-imagination, Prainsack draws attention to how *not* doing or saying something ‘naturalizes specific distributions of power and agency, and suggests that those are behind our control’ (Prainsack 2022, 24). In the hearing, the omission of the ecological crisis naturalises the preservation of human lives in the global north as morally and materially privileged and distinct from warming oceans and fraying ecosystems. In practice, precision medicine is operationalised toward sustaining the particular human life and treating that ‘life’ as belonging to a different moral domain than ‘earth’. This ‘imaginative hegemony’ (Prainsack 2022, 26) shows us how a vision of the common good, when configured through the lens of national and individual survival, becomes incommensurable with the notion of a planetary common good.

Earth-life relationships in medical anthropology in the global north

Prioritising human lives over planetary ecosystems is at the core of the ecological crisis. In that respect, the vision of precision medicine that unfolded at the Danish Parliament contained a familiar moral myopia. For us, the non-imagined terrestrial future at the hearing raises questions about what kinds of life and ways of living are selected, promoted, privileged, and kept in existence. While the hearing alerts us to the non-imagined (non)human lives and ecosystems in precision medicine, it also made us wonder about the role of non-imagined lives and ecosystems in medical anthropological analyses. The hearing showed us that the common of the ‘common good’ was performed as a human public belonging to a national and politically demarcated community. So what notions of the common good inform our own analyses?

Grappling with questions like these pushes our ‘anthropology mind’ to ask how we might approach life as both social and terrestrial. Studies in the growing field of environmental anthropology have generated rich insights into how humans and other beings live in environments; scholarship which has theorised dependencies among life-forms and between life-forms and ecosystems (Tsing 2015; Chao 2022; Papadopoulos 2021) and unpacked a late-liberal ‘geontological’ separation of living and non-living (Povinelli 2016). While this scholarship has suggested exciting analytical handles of thinking with soil (Salazar et al. 2020), ghosts, and monsters (Tsing et al. 2017), it is primarily oriented towards the mutual shaping of landscapes and communities and of intra-species socialities. It does not explore the terrestrial entanglements of medical practices. Medical anthropology, in turn, has called for attention to the effects of climate change on human health. In particular, medical anthropologists have exposed how climate change affects the poor and those who live in areas prone to pollution or extreme weather, including flooding, fire, heat, and drought, as well as zoonotic disease, migration, and shortages of food, water, and living space (e.g., Hinchliffe et al. 2021, Nading 2023, Singer 2014). Most of these studies are situated in the global south, among indigenous people, or populations who experience the ‘embodied inequalities’ (Segata et al. 2023) and ‘structural vulnerabilities’ (Evia 2023) of climate and ecological changes. By contrast, we have not come across scholarship that discusses how commitments to and technologies of human health, such as precision medicine, intervene upon who and what will come to inhabit our planet.

As such, the non-imagined terrestrial future we witness in precision medicine is paralleled by a non-imagined terrestrial future in anthropological and social science studies of the life sciences. The political hearing on precision medicine drew our attention to our own epistemological standpoint, from which we investigate humans as patients, agents, subjects, citizens—but not earthlings, who are always enveloped by, engaged with, and dependent on ecosystems. Social science studies of the life sciences have produced strong analytical frames for investigating the governance of life (Rose 2007; Murphy 2017) and data (Hoeyer 2023; Ruppert and Scheel 2021) and the moral striving of human actors who as scientists, health professionals, patients, and citizens become part of the life sciences (e.g., Rapp 1999; Franklin and Roberts 2006; Wahlberg and Gammeltoft 2018; Kerr et al. 2021; Svendsen 2022). This expertise is more needed than ever. But isn’t it time to also theorise the earthly connection—the terrestrial entanglement—of the ‘life’ and ‘life politics’ at the centre of anthropological studies of the life sciences? This involves, we believe, extending our focus from the government of life in politics, labs, and clinics to the government of earth-life.

In their discussion of future studies of the governance of life, Villadsen and Wahlberg point to the importance of attending to not only ‘life’, but ‘living’, including the environmental limits of a population (Villadsen and Wahlberg 2015, 14). Such an earth-life framework, as we would name it, starts from the proposition that we need to ask curious questions about and take seriously ecosystems as belonging to the ‘life’ we investigate. In this framework, the ‘world-part’ of our much-used concept of ‘lifeworld’ should not only include social relations, temporal horizons, legal frameworks, and the sociomaterial networks of technology, but also the naturecultures that we and our interlocutors interact with—even if they are silenced or non-imagined. With inspiration from STS, ethnographic studies of the life sciences in the global north have explored the inseparability of humans and other life forms (e.g., Franklin 2007, Friese 2013, Kaufman 2005, Sharp 2018, Svendsen 2022), but not necessarily attended to the ecological world. They have taken an interest in what it means to be human with new technological advances, but they have not explored the constant conscription of organic and inorganic matter involved in the production of these specific humans’ lives and health. They have not taken great interest in how the benevolent agendas of life-extension enact distinctions between who and what will be devoured by growth, and what will be sustained. They have not attended to the earthly connections of the life science technologies they study.

We believe that unfolding ecological troubles calls for a renewed attention to the relationship between ecological crisis and health in the global north. We need to bring literatures from environmental humanities and medical anthropology into interaction. One first step in that direction is to address what nobody in the hearing on precision medicine imagined as relevant: that the practices and moral imperative of extending lives in the global north are implicated in the deaths of other humans, species, and ecosystems. From an earth-life perspective, we must articulate new imaginations and rethink the ‘common good.’

Authorship statement

Mette N. Svendsen took the lead in developing and writing the Position Piece. Both authors jointly edited, revised, and responded to reviewers’ comments.

Ethics statement

According to Danish law, qualitative research is not subject to an official ethical review. The study is reported to the Danish Data Protection Agency and follows the Danish rules for ethical conduct (informed consent and anonymisation of participants).

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