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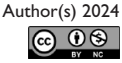

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Population curation: The construction of mutual obligation between individual and state in Danish precision medicine

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Abstract

How do precision medicine initiatives (re)organize relations between individuals and populations? In this article, we investigate how the curation of national genomic populations enacts communities and, in so doing, constructs mutual obligation between individuals and the state. Drawing on ethnographic fieldwork in the Danish National Genome Center (DNGC), we show how members of advisory bodies negotiated the inclusion criteria for two different genomic populations: a patient genome population and an envisioned 'Danish' reference genome population. The patient genome population was curated through a politics of inclusion, of as many genomes as possible, whereas the reference genome was to be curated through a politics of exclusion, to include only the genomes of 'ethnic' Danes. These two data populations configure differently the community of 'Danish patients' who might benefit from precision medicine, and thereby prescribe different moral continuities between person, state, and territory. We argue that the DNGC's patient genome population reinforces reciprocal relations of obligations and responsibility between the Danish welfare state and all individuals, while the proposed Danish reference genome population privileges the state's commitment to individuals with biographical-territorial belonging to the nation-state. Drawing on scholarship on social and health citizenship, as well as data solidarity in the Nordics, the discussion shows how population curation in national precision medicine initiatives might both construct and stratify political obligation. Whereas STS scholarship has previously deconstructed the concept of 'population', in the context of the troubling and violent effects of the management of human populations, we point to the importance of population

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curation as a vehicle for making the individual legible as part of a community to which the state is responsible and for which it is committed to care.

Keywords
Population curation, genomics, community, precision medicine, Denmark, welfare state

How do precision medicine initiatives (re)organize relations between individuals and broader populations? The current efforts in biomedicine to tailor prevention, diagnosis, and treatment to individual patients depend on unprecedented amounts of population data, specifically genomic data (Dickenson et al., 2018; Prainsack, 2017). In response to this need, countries worldwide are establishing national repositories of their populations' genomes. These national genomic populations are seen as key to bringing emerging knowledge of individual genetic variation into clinical application, and countries as diverse as the US, the UK, China, Australia, Japan, Saudi Arabia, Estonia, France, Dubai, and Turkey have launched national programmes for collecting at least 100,000 genomes of their populations (Philippidis, 2018). Much STS scholarship has poignantly shown how biomedical research into population genetics has, even unintentionally, reinforced discriminatory notions of race, ethnicity, and gender (Burton, 2021; Hinterberger, 2012; M'charek, 2005; Nash, 2015; Oikkonen, 2018; Reardon, 2017). In this article, we take Denmark as a case study to tell a different story. By investigating how genomic data populations are curated through criteria for inclusion and exclusion in a national precision medicine institution, the Danish National Genome Center (hereafter DNGC), we bring to the fore how genomic populations enact communities, and construct reciprocal and mutually binding relations between individuals and the Danish welfare state.

Denmark is promoted as one of the most digitized and data-intensive countries globally, and is known for its comprehensive registration of citizens for medical, organizational, and administrative purposes (Hoeyer, 2023; Terkildsen et al., 2020). Strong voices in policy, science, and industry argue that the abundance of Danish health data, combined with high levels of trust in the Danish state and the governing authorities, provide exceptional possibilities for realizing precision medicine (Ministry of Health and Danish Regions, 2016). In 2019, the DNGC went into operation as a governmental agency, envisioning two different genomic populations. First and foremost, the DNGC collects and stores the genomes of Danish patients who, as part of their treatment in the publicly funded healthcare system, are subject to advanced genetic analysis. Besides this patient genome population, stakeholders within the DNGC attempt to create a 'Danish reference genome', representing the distinct average 'Danish' genetic variation to be used in research and clinical care. Whereas the patient genome population began to accumulate in 2019, the Danish reference genome has yet to materialize.

The DNGC stores and collects only digitized genomes and is thus not a biobank. Upon providing written, informed consent, patients' genomes are sequenced locally in the healthcare system and then transferred digitally to the DNGC. The blood samples used for sequencing remain in local storage. The DNGC was established as the cornerstone of Denmark's political strategy to realize precision medicine—according to which, precision

medicine should be 'of benefit to the patients' (Ministry of Health and Danish Regions, 2016). The overall aim of the DNGC is thus to improve patient treatment by increasing the use of genomic information in the clinic. Every citizen in Denmark—in fact, everyone with legal residency in the country—is entitled to publicly funded healthcare services (Ministry of the Interior and Health, 2022), and hence everyone living in Denmark is either a current or a potential patient. Thus, 'Danish patients' constitute a universal, all-inclusive community of Danish citizens and people registered as living on Danish territory, for whom the state is committed to providing care. The DNGC's two data populations—the patient genome population and the proposed reference genome population—are thus intended to serve this larger political community of the national population (*befolkningen* or *folket* in Danish) (Burton, 2021; Svendsen & Navne, 2023; Tupasela, 2021).

Between 2018 and 2020, all four authors were granted access to follow, for ethnographic purposes, the politico-administrative process of establishing the DNGC. Drawing on fieldwork conducted in advisory bodies in the DNGC, we explore how members of these advisory bodies negotiated the inclusion criteria for the patient genome population and a potential reference genome population. The questions we ask are: How do members of advisory bodies curate the DNGC's genomic populations, and what communities of 'Danish patients' do these data populations delineate and enact? How does genomic population curation construct relationships between the individual and the welfare state by prescribing reciprocal relations of obligations, responsibilities, and commitments? We demonstrate that members of the DNGC's advisory bodies curated the patient genome population through a politics of inclusion to ensure a universal data population. In contrast, the reference genome population was proposed to be curated through a politics of exclusion to selectively include only 'Danish' genomes, that is, genomes of 'ethnic' Danes. The scientific rationale behind this exclusion is that a sample population restricted to ethnic Danes will be genetically homogeneous and allow for the detection of hitherto unknown genetic variations of clinical significance. The practice of using ideals about genetic homogeneity or heterogeneity to guide population genetic research is by no means new. As Shim et al. (2014, p. 580) have argued in this journal, genetic homogeneity and heterogeneity are 'situational properties that scientists seek to achieve in their study populations.' Several social science studies of population genetic research have examined how nations, research institutions, and researchers construct population isolates as either genetically homogeneous or heterogeneous, and in some instances, both. These studies have pursued two main interests: first, how the construction of genetic difference comes to reinforce notions of ancestry, origin, and thus race (e.g. Gibbon, 2016; Hinterberger, 2012; Montoya, 2011; Reardon, 2005; Tsai, 2010), and second, how nations promote the genetic uniqueness of their population isolates to leverage competitive advantages in an increasingly globalized research market (Helén et al., 2024; Tarkkala & Tupasela, 2018; Tupasela, 2017, 2021).

These studies teach important lessons about the role of genetic research in forming national communities and in constructing racialized and contested stories of origin, ancestry, and belonging (for the co-constitution of human genetics and nationalism, see Burton, 2021; Nash, 2015; Oikkonen, 2018). Much less attention has been given to the ways in which the curation of populations for genetic research to advance precision medicine constructs particular relationships between individuals and the nation-state. To

fill this gap, we explore how the DNGC's genomic populations enact who constitutes 'Danish patients', what citizen obligations are implied for the individuals who belong to this national community, and what commitments characterize the welfare state's responsibility towards it. Despite being curated within the very same institution and seeking to improve the health of the same national community of 'Danish patients', the DNGC's patient genome population and the envisioned reference genome population demarcate two different versions of it. The community enacted by the inclusive patient genome population is universal, as it encompasses everyone with access to healthcare services. This population reinforces reciprocity between the individual and the state as people make themselves available as data providers for the DNGC, and thus the Danish state, in exchange for publicly funded healthcare. In contrast, the community of 'Danish patients' enacted by a genetically homogeneous reference genome population would include only ethnic Danes, selectively demarcating this group as worthy subjects of state care and commitment. We argue that the criteria for inclusion and exclusion applied to curate the DNGC's genomic populations reinforce mutually binding relations of obligations and responsibility between the individual and the state, while—simultaneously—the potential realization of a genetically homogeneous reference genome population would privilege the welfare state's commitment to those with biographical-territorial belonging to the nation-state. This argument foregrounds how precision medicine's genomic populations might stratify the social contact between individuals and the state by rendering possible categorizations along the lines of ancestry, origin, and race, and enacting a politics of belonging (Yuval-Davis, 2011) that prescribes *different* moral continuities between person, state, and territory (Svendsen & Navne, 2023).

First, we present our approach to population curation as a practice of constructing data populations that enact national communities, and show how the enactment of such communities implies normative relationships between individual and state. Second, we outline our study and the context of data population politics in the Danish welfare state. Third, we analyse how members of the DNGC's advisory bodies negotiated the inclusion criteria applying to the patient genome population and the proposed Danish reference genome population. Before concluding, we draw upon scholarship on social citizenship, health citizenship, and data solidarity to unfold how genomic populations might both construct and differentiate political obligation.

Data population curation

Although precision medicine draws the individual into focus, data populations are prerequisites for knowing the individual (Hoeyer, 2019; Parry & Greenhough, 2018). Drawing upon Deleuze's (1992) concept of 'dividuals,' Bauer (2014) emphasizes the mutual construction of individual and population, arguing: 'Individual and population can no longer be conceived as opposites, as even in the often envisioned individualization and personalization of diagnosis and treatment, this "dividual body" is reassembled and enacted through statistical strata and distributed bodies stored in bio-banks' (pp. 206–207). Precision medicine is thus occasioning an unprecedented 'traffic in populations' (Hinterberger, 2012, p. 74). Yet, although biomedical, epidemiological and life science knowledge production takes data populations as the natural object of study, in

her seminal article 'Who and what is a "population"?', Krieger (2012) exposes the paradox that the concept of 'population' is rarely discussed or defined in the population sciences. Science studies scholars, however, have demonstrated how (data) populations constitute epistemic artifacts produced by the very technologies that seek to encircle them: there is no natural way of grouping humans into populations, and they do not embody or represent 'meaning' beforehand. Rather, it is the very acts of categorizing and establishing populations that imbue human genomes with a particular meaning and value (Hinterberger, 2012; M'charek, 2005; Reardon, 2017; see also Epstein, 2007). Along similar lines, Clarke (2018, p. 32), discussing population, argues that: 'many robust scientific worlds are organized *through* use of that concept', and therefore, its meanings need to be deciphered.

The ways in which data populations are imbued with meaning and value are inextricably linked to the institutions managing their establishment. Researching the history of statistical reasoning, Hacking (1990) notes that, at first glance, the topic of population is seemingly 'unproblematic' and obvious, yet: 'even the very notion of an exact population is one which has little sense until there are institutions for establishing and defining what "population" means' (p. 6). Precision medicine initiatives such as the DNGC epitomize the historical relationship between statistics and governmental power, in which numerical descriptions of populations provide the basis for political intervention and action (Desrosiéres, 1994; Hacking, 1990; Porter, 1986; Ruppert & Scheel, 2021). Approaching the population as a political problem, Foucault (2003) demonstrated how the population—the collective body politic—became an object of government and control through the rise of statistical methods and knowledge, including estimates and overall measures of, for instance, birth and death rates and average life expectancy. Yet as Ruppert (2011, p. 219) has argued, Foucault 'did not investigate the specific practices that make it possible to know and then act upon populations'. She calls for attention to both the object and subject effects of enumerative population practices, demonstrating how the making of populations is a 'particular way of organizing social relations' (p. 220).

In the following pages, we explore how the curation of genomic populations in Denmark (re)organizes social relations in the welfare state. To do so, we draw upon social studies of population genetics, demonstrating how the scientific practices of identifying genetic variation in human populations enact belonging and communities, and how such practices sustain nationalism through descriptions of human populations according to geography and ancestral history. Studying the co-constitution of nationalism and human genetics, Burton (2021) describes that to produce useful, generalizable knowledge, 'geneticists must constantly decide which individuals "belong" to the population and which should be excluded' (p. 5). This drawing of boundaries around genetic populations is not straightforward; apart from scientific arguments, it mobilizes and draws upon biological, social, and cultural assumptions about people and places (Burton, 2021, p. 5). Negotiations of both inclusion and exclusion criteria invoke the question of which lives are worth recording, and thus, who counts (Cool, 2022). In her book *Population genetics and belonging*, Oikkonen (2018) shows how the technoscientific practices of population genetics enact communities in different ways. She argues that 'population genetics is flexible as an affective resource in that it can be mobilized

to support multiple communities; yet the material conditions of population genetic knowledge production—techniques, samples, methods, practices—shape those communal projects in fundamental ways' (p. 176). When governmental institutions such as the DNGC compose national genomic populations, these populations simultaneously engender particular kinds of communities, whether such 'imagined communities' (Anderson, 2006) constitute a people, a society, or a nation (Hacking, 1990).

Studies have investigated how population genetics both enables and constrains the imagination and enactment of belonging through categories of race and ethnicity, alongside claims to ancestry and geographical origin. Here we trace how genetic or genomic populations, and the communities they enact, create mutually binding relations between individual and state: Who belongs to the genomic populations established through national precision medicine initiatives? What communities do these genomic populations delineate and enact, and what relations between individual and state do these communities entail? We suggest the term 'population curation' as an analytical means to engage these questions. Population curation exposes what is easily concealed in scientific practices: namely, that the criteria for inclusion and exclusion, which draw boundaries around genomic populations, enact normative individual-state relations of obligations, belonging, and commitments (see also Lee, 2021; Pinel & Svendsen, 2021). To make this argument, we draw upon Leonelli's (2012, 2016) seminal work, demonstrating how the subjective judgments carried out by data curators have profound epistemological effects that actively shape the creation, perception of, and use of data. Data curation is broadly defined as processes of 'caring' for data (Fortun, 2023), and it often describes activities such as formatting, cleaning, and organizing data sets so that they can be 'packaged' for new kinds of use and users (Leonelli, 2016; Leonelli & Tempini, 2020; Tempini, 2021). Here, we expand 'data curation' to capture not only activities relating to data collection or activities taking place 'close' to the data after they have been brought into being, but also the politico-administrative negotiations defining what data should come into existence in the first place. As opposed to the terminology of 'collecting', 'selection', or 'sampling,' 'curating' brings into focus that the establishment of data populations draws upon and actively continues culturally specific meanings and values of societal organization (Gjødsbøl, 2023): The criteria for inclusion and exclusion applied to national genomic populations simultaneously reflect and enact who belongs in society, who the individual is in relation to the state, to whom the state is responsible, and thus, the reach of the welfare state. Before we turn to the curatorial data practices in the DNGC, we account for our study and the data population politics in Denmark's welfare state.

The study

As part of the process of establishing the DNGC, different advisory bodies were convened in 2017 and 2018 to ensure inputs from a broad range of stakeholders with an interest in precision medicine: healthcare professionals already working with or aspiring to use genetics and genomics in their health services; researchers doing basic and applied biomedical research; patients and citizens engaged in precision medicine and interested in the establishment of the DNGC; and practitioners and researchers addressing the ethical implications of collecting, storing and using health data and particularly genetic

information. Meetings of these advisory bodies were not spaces for political decision-making. Rather, the officials employed in the DNGC used these meetings to seek advice and inputs from stakeholders on how to establish a national infrastructure for genomic data in ways that these stakeholders rendered supportive and meaningful for their work, and in ways that patients and citizens rendered socially and ethically robust.

All authors were granted access to one or more of the DNGC's advisory bodies: Gjødsbøl, Skovgaard, and Svendsen observed meetings of the Professional Board [Fagligt Udvalg], Gjødsbøl and Svendsen observed meetings of the Research Committee [Forsknings- og Infrastrukturudvalget], Skovgaard observed meetings of the Patient and Citizen Advisory Group [Patient- og Borgerudvalget], and Knox and Svendsen observed meetings of the Ethics Committee [Etikudvalget]. On average, meetings lasted between two and four hours. In total, one or more of the authors were present at the following: four meetings of the Professional Board, 10 meetings of the Research Committee, five meetings of the Patient and Citizen Advisory Group, and 15 meetings of the Ethics Committee. As the Principal Investigator of a research project investigating the social and ethical implications of precision medicine, Svendsen was appointed to the Ethics Committee and the Professional Board and participated in these as would any other member. In these meetings, our presence was therefore characterized by a dual position, in which observation and participation took place simultaneously.

In addition to the observations and informal conversations with actors in relation to meetings, Gjødsbøl, Skovgaard, and Svendsen conducted semi-structured interviews with stakeholders in Danish precision medicine who use or will use the DNGC's genomic data. We interviewed clinicians, researchers, and officials who strive to further precision medicine in Denmark, and some but not all of these stakeholders were members of one of the DNGC's advisory bodies. In total, we conducted 30 interviews, many but not all of which were conducted by two of the authors in collaboration. These interviews lasted between 25 and 90 minutes, typically for one hour. Our study has been approved by the Danish Data Protection Authorities. Formal ethical approval is not required under Danish Law.

Data population politics in the Danish welfare state

Denmark is a welfare state that presupposes relations of reciprocity between citizens and the state (Bendixen et al., 2018). Welfare services such as healthcare, child- and eldercare, and education and unemployment benefits are publicly funded or subsidized by the state through high levels of taxation of income. Everyone registered in the Central Person Registry [Det Centrale Personregister; Folkeregistret], or with permanent residency in Denmark, has universal access to healthcare services (Ministry of the Interior and Health, 2022). When using these services, patients deliver and share their health data with the authorities, meaning that access to healthcare is conditioned upon having one's health data registered and stored in numerous registries. In Denmark, and Scandinavia more broadly, the collection and management of data populations are inextricably linked to the emergence of the welfare state in the twentieth century and its continued maintenance. The establishment of universal population registries and the exceptional opportunities for linkage between them through a personal identification

number—the CPR number, in Denmark issued through the Central Person Registry—have been fundamental tools for developing and appropriating administrative data and infrastructures into a distinct 'Scandinavian epidemiology' (Bauer, 2014; see also Alastalo & Hélen, 2022, for an analysis of personal identity numbers and their significance for both individualized care and state governance in the Nordic welfare states). As argued by Cool (2016, p. 282), the 'obsession' with collecting ever more data in Scandinavian states must therefore be understood in the context of these states' political systems being 'characterized by an intimate "science-state nexus"' (Asdal & Gradmann, 2014). In Denmark, the establishment, maintenance, and use of data populations for research are considered significant means by which to provide and secure high-quality public healthcare, and political efforts have been and are continuously being made to increase the opportunities for repurposing data—that is, using data collected for one purpose (i.e. medical treatment) for other purposes (i.e. billing, quality assurance, and research) (Hoeyer, 2023; Nordfalk et al., 2022; Snell et al., 2023). The genomic data collected and stored in the DNGC are expected to further enrich the 'goldmine' of already existing Danish health data and provide a competitive advantage in global biomedical and life science research and innovation (Tupasela, 2021). The building of a national infrastructure for the storage, use, and governance of genomic data within a state institution has thus become a significant tool to 'brand' Denmark as a distinct nation for which the cultivation of health and wealth constitute two sides of the same coin (Tarkkala et al., 2019; Tupasela et al., 2020).

Danish health data from registries can be used for research without consent from the individual and approval from an ethics committee (National Committee on Health Research, 2024). If citizens want their biological samples or genetic data to be used only for their own treatment, and thus not for research, they can opt out by registering in the 'Tissue Application Register' [*Vævsanvendelsesregistret*] (The Danish Health Data Authority, 2024). This means that in practice, the only way to opt out of research populations in Denmark is to become included in yet another registry population. The first version of the bill aimed at establishing the DNGC by law proposed an opt-out solution to data collection—what Skovgaard and Hoeyer (2022, p. 3) term a 'lenient legal framework'—in which the responsibility for knowing about the right to opt out rests with the patients. This legal framework would allow for the automatic transfer of genomic data into the DNGC when patients become subject to advanced genetic analysis as part of their healthcare, and ensure universal collection of patient genomes known from other types of health data. In light of the Danish tradition of harvesting data from citizens' interactions with state institutions, including the healthcare system, there should be nothing revolutionary about a new national genome database. Yet, the proposed legal framework for the DNGC sparked a heated public debate about 'data authority' (Skovgaard & Hoeyer 2022, pp. 1–2), which refers to the 'collection or use of data, which is deemed right and just by the populace affected' (for a detailed analysis of the public debate, see Skovgaard & Hoeyer, 2022; Svendsen & Navne, 2023). Critical voices demanded that, because genomic data are especially personal and sensitive, patients should be obliged to grant active informed consent before delivering data to the DNGC, otherwise the transfer of data would be equivalent to the state 'stealing' citizens' DNA (Beich & Kristiansen,

2017). In response, the Danish Parliament decided that patients have to provide written consent to whole genome sequencing (WGS), and be explicitly informed about their possibility of joining the Tissue Application Register (Ministry of the Interior and Health, 2019). In practice, what patients consent to is genomic analysis—not to having their genome stored in the DNGC, though storage is a necessary condition for having genetic analysis performed within publicly funded healthcare.

The genomic populations in the DNGC are intimately connected to the clinical space, first because they are produced through clinical encounters between patients and healthcare professionals, and second, because these data populations explicitly aim to be of 'benefit to the patients', and thus enhance clinical treatment. In what follows, we analyse how members of the DNGC's advisory bodies negotiated the inclusion criteria applying to two different populations, thereby enacting an intended identical community of 'Danish patients': a patient genome population and an envisioned Danish reference genome population.

The patient genome population

To establish the DNGC's patient genome population, members of the Professional Board had to settle on which individuals to include in the population and what kinds of genetic data to collect and store. As we shall see, the patient genome population was curated through a politics of inclusion. Yet the question of how to act out such all-embracing inclusion criteria in the clinic raised moral dilemmas, exposing not only Danish citizens' obligations as data providers for the state, but also the welfare state's moral obligations towards its citizens.

Including individuals: Exchanges of healthcare services and data

In the late summer of 2018, the DNGC held two meetings of the Professional Board. One practical objective of these meetings was for the board members to draft a new informed consent form to be used in the clinic for patients who, as part of their care, become subject to WGS. In doing so, board members recurrently discussed the Tissue Application Register. Presenting a draft for the informed consent form, one of the DNGC's officials explained that they had deliberately not included a checkbox for the Tissue Application Register to ensure greater effort was required for people to withdraw their consent to having their data used for research. As a response, a board member pondered:

> What is the task of the health professionals here? To guide people toward the Tissue Application Register or to let it be people's own civic duty? [As I see it], the purpose of the consent form is that it should remain a little troublesome to become part of the Tissue Application Register.

In negotiating the consent form's level of information about the possibilities for opting out of the DNGC's patient genome population available for research, board members sought to reach a balance between informing patients about their right to—and how to—decline the use of their genomes in research, and nudging people away from using this

right. While there was consensus among board members that patients should be informed about the Tissue Application Register, there was an equally strong consensus for not highlighting its existence. Board members thus curated the patient genome population through a politics of inclusion, striving to quickly include the greatest possible number of patient genomes in order to assemble a representative population that was unaffected by selection bias and opt-outs.

Like Denmark's other health data populations, board members render the DNGC's patient genome population valuable for research and clinical use because it includes every resident entitled to WGS through publicly funded healthcare. This approach to data collection echoes Denmark's traditions of turning patients' use of healthcare services into data points and of universally registering citizens' health data to uphold unique possibilities for performing representative research (Nordfalk & Hoeyer, 2020). Due to the broad coverage of the population in the Danish registries, and the comprehensive registration of citizens from cradle to grave, Denmark has been described as 'the epidemiologist's dream' (Frank, 2003), and as an entire 'cohort' (Frank, 2000). Board members' curation of the patient genome population is thus bound to the healthcare structure of the welfare state (Burton, 2021), confirming and continuing the state's responsibility to provide its services to a universal community of Danish patients. By *not* selecting among individuals, the patient genome population accrues value in virtue of its universal coverage, meaning that in the course of time, the data population sample accumulates to become representative of the national population.

The informed consent form details the practical and mundane data work that takes place in the clinic: the work and processes undertaken by health professionals and patients to extract and deliver human tissue to be turned into samples, and eventually, digital genomic codes stored in the DNGC. For board members, drafting the consent form entailed balancing the individual patient's statuses as a data provider for the welfare state and as a citizen with claims to the state's care and protection. In another meeting of the Professional Board held in November 2018, a member voiced his concern about the fact that patients who do not want their genomes stored in the DNGC should not have access to WGS in the context of public healthcare. He asked the manager of the DNGC:

> In all seriousness, do you mean that people cannot decline to have their data stored in the DNGC? It's very dramatic if people who do not want to have their data stored in the center cannot have their diagnostic tests and treatment. (DNGC Professional Board member)

This comment gave rise to a discussion among board members about whether it is at all possible to receive healthcare services in Denmark while avoiding patient information being stored in medical records and thus publicly administered databases and registries. A board member also serving as legal adviser in health law explained:

> This is no different from what happens in other places in the healthcare system. The only difference is that in this case, consent [to a medical procedure] is written; otherwise, it's oral. In other situations, it's not possible to enter the clinic saying that one must not be registered in clinical databases. (DNGC Professional Board member)

While Denmark is known for its digital infrastructures and the amounts of health data produced and exchanged, the discussion among board members exposed the opaque nature of the accumulation of data populations resulting from Danish citizens' interactions with state institutions. The fact that even the advisory board members working as healthcare professionals were unconscious of the registration practices permeating their own clinical work speaks to the naturalness of these practices, taking place without notice as when, for instance, an individual receives treatment in a hospital or dies of a medical condition, and thus becomes a set of abstract data points in registries and databases. The negotiations about the inclusion criteria applying to the DNGC's patient genome population elucidated and cemented the otherwise taken-for-granted, yet binding relations of obligations, responsibilities, and commitment between the individual and the welfare state: Patients are expected to serve as data points in various data populations within state institutions in return for publicly funded healthcare services, while the state renders individuals as data points to be organized into data commons which can be mobilized to improve public health (Hogle, 2016). In what follows, we turn to board members' negotiations of how to collect as many genomes (instead of less complex genetic data) in the DNGC as possible, demonstrating that in a welfare state, data points cannot easily be detached from bodies. Rather, the patient genome population enacts a universal community of Danish patients and tethers this community to the state by reinforcing mutual moral commitments between the individual and the state.

Tethering individual to state and state to individual: 'Danish patients' as a universal community

Concurrently with the discussions about informed consent, the DNGC's advisory bodies had to make recommendations about what kinds of genetic data to include in the center. Members of the Professional Board struggled to agree on what constitutes a useful and valuable genetic population—in the present and the future—and kept discussing what types of data the DNGC should store: whole genomes, exomes, gene panels, single genes, proteomics, RNA, raw data, or processed data. Especially for the researchers present, the uncertainty about the future value and relevance of the imagined data populations supported the case for including too many types of data instead of too few. In a meeting in August 2018, one board member suggested that researchers and clinicians cease doing simple genetic analyses, and instead that gene panels or WGS on all patients should be run once and for all—not to make use of this 'surplus' information in the clinical setting in the present, but to save it for future clinical use and research purposes. This approach echoes what Hoeyer (2023) has coined 'intensified data sourcing' and brings to light how data do not fit into finite categories of either clinical or research. Clinical data are always already thought of as research data—they belong simultaneously in both categories and hold potential for both domains through the possibilities for data flow between them (Pinel & Svendsen, 2021).

While some board members agreed that running WGS on all patients would speed up data collection, and thus create the most comprehensive patient genome population, others were more reluctant. Because active, written, and informed consent is required for data to flow into the DNGC, board members with ties to the clinic argued that running

WGS by default would burden the entire healthcare system, including professionals and patients, with bureaucratic consent procedures not measuring up to the clinical value of collecting and storing these data in the DNGC. One board member stated: 'Another issue is the patient group. If we do it [WGS], we'll find a lot of secondary findings. Then it begins to appear like population screening.' Screening is a way of examining a population of apparently healthy people to identify those at risk, and to initiate prevention, examination, or treatment. Whereas some board members saw opportunities in collecting and storing as many whole genomes as possible, others stressed that the accumulation of such data places obligations on clinicians to treat the individuals comprising the patient genome population not only as abstract data points, but as identifiable persons and bodies who might benefit from having significant knowledge returned to them.

Comparing the patient genome population to screening, the board member emphasized that the welfare state's data practices entail moral and organizational responsibilities to put in place national procedures for responding to the individuals in this population, instead of letting them seek out information themselves. As opposed to screening procedures that aim to detect specific diseases, doing WGS by default would create a 'surplus' of knowledge that has not been requested by anyone. Yet even the non-requested knowledge produced within state institutions cannot escape the moral obligation of the state to act in the interest of its healthcare-seeking and data-providing residents. The clinically unspecified purposes of patient genomes thus acted as an unlimited future research potential while also calling the legitimacy of the data population into question. In board members' negotiations of the inclusion criteria, the imagined 'population body' shifted from being perceived as constituted by an uncountable and thus unidentifiable number of 'heads'—that is, abstract data points—to discrete individuals-as-bodies (Foucault, 2003, p. 245) entitled to receive healthcare services and relevant health information, and to be shielded from harmful knowledge. As opposed to the point made by Nordfalk et al. (2022, p. 14) that 'storage disentangles data from people', board members were aiming to tether individuals to the welfare state by calling upon the state's moral responsibilities and commitments towards the community of Danish patients.

The curation of a universal patient genome population rendering all Danish patients eligible for inclusion thus substantiated existing reciprocal relations of exchange between individual and state. Unlike the debates about how data might be mobilized and exploited without consideration for the bodies from which data originate (see Kahn, 2014; Nafus & Neff, 2016; Rabinow & Rose, 2006), our case illustrates that the DNGC's curation of the patient genome population re-articulates a national welfare state collective inhabited by people to whom the state is committed. For the individual, to be included in a data population is a way of enrolling in a larger welfare state collective defined by mutually binding and thus reciprocal relations. Much social science literature on precision medicine and data practices has problematized issues such as who should own, control, and benefit from data, and thereby cautioned against how the selective curation and use of populations for genetic research risks jeopardizing notions of trust and solidarity (Lee, 2021; Lee et al., 2019; Prainsack & Van Hoywegen, 2020; Reardon, 2022; Snell et al., 2023). Our analysis of the politico-administrative negotiations of the inclusion criteria applying to the DNGC's patient genome population brings to light how, in the context of the Danish welfare state, all are universally eligible subjects: The community of Danish

patients and its social contract are not up for discussion, since everyone is expected to contribute and gain benefit.

We now turn to the DNGC's attempt to create a Danish reference genome, demonstrating how members of advisory bodies shifted the inclusion criteria for this population to operate through a politics of exclusion.

The Danish reference genome population

The strong political focus on precision medicine's benefit to Danish patients meant that, at least initially, the DNGC should only collect genomes from patients, leaving out the possibility of including genomes from healthy individuals for research purposes. However, this decision made little sense to some of the members of the Research Committee, who argued that without a healthy control population to compare to the 'sick' patient population, the latter would be of little value. In response, in 2019 this committee initiated a project seeking to establish a 'Danish reference genome' to map the unique genetic variation of the Danes in Denmark, and suggested curating the reference genome population from a cohort of Danish blood donors who consent to participate in genetic research. Whereas the patient genome population was deemed valuable because of its universal inclusion of individuals, some committee members argued that the value of the reference genome population rests in the genetic *homogeneity* between individuals. This argument builds upon the rationale that a genetically homogeneous population will reduce genetic 'noise' (referring to random variation), and thus increase statistical power for discovering novel disease-causing genetic variation (Hinterberger, 2012; Tarkkala & Tupasela, 2018; Zara, 2015). As with the patient genome population, the curation of a reference genome population entailed negotiations of which individuals to include and how.

Including individuals: Genetic sameness and difference along territorial lines

The idea of creating a Danish reference genome expands on an article describing a Danish reference genome, published in 2017 in *Nature* (Maretty et al., 2017). This reference genome was the outcome of the research consortia GenomeDenmark, a conglomerate of universities and private companies. GenomeDenmark included the Chinese world-leading sequencing firm BGI Genomics, which placed its European headquarters in Copenhagen in 2010, in part because of its involvement in GenomeDenmark (Svendsen, 2023; Tupasela, 2021). The reference genome was made through in-depth sequencing of 50 Danish 'trios' consisting of a father, mother, and child. In the article in *Nature*, the authors state that the primary goal of a regional reference genome is to improve the clinical interpretation of disease-causing genetic variants in Danish patients by replacing the current use of a single—and thus international—reference for the human genome (Maretty et al., 2017). Some of the actors involved in GenomeDenmark were members of the DNGC's advisory bodies, from which positions they continued their efforts to make an expanded version of a Danish reference genome.

At a meeting of the DNGC's Research Committee in March 2019, a bioinformatician was invited to give a presentation entitled 'Rare human variation'. He explained that a Danish reference genome made by sequencing 10,000 genomes of healthy individuals would constitute a 'catalogue of genetic variation in the Danish population', and serve at least two purposes: first, compared to the genomes of sick patients, genetic variation of healthy Danes could be used to decipher what makes people sick, and second, to discover new and hitherto unknown genetic variation in the Danes. The rationale behind the Danish reference genome thus asserts that what it means to be Danish is biologically unique and different from being Swedish, Norwegian, German, and so forth—and that valuable medical knowledge accrues from understanding and appropriating this difference (Epstein, 2007; Hinterberger & Porter, 2015; Taussig, 2009). Yet, what constitutes such distinctive 'Danishness' was not entirely clear for one committee member, who responded to the bioinformatician's presentation, asking: 'What is it to be Danish? Is it the passport, citizenship—what constitutes Danishness?' With these questions, the committee member drew attention to the fact that biological Danishness is not a natural fact to be read out of the genomic code, but rather something approximated and defined by social, cultural, and legal characteristics (M'charek, 2005; Reardon, 2017).

The question of what it means and takes to be inherently Danish was raised several times in various meetings, yet never directly answered. In the late summer of 2020, members of the Research Committee convened again and came closer to an answer. Before the meeting, the DNGC had prepared an appendix outlining a 'technical analysis' of the Danish reference genome. The appendix raised the centrally important question of whom to include in the reference genome population—a practical question that translates into the general, theoretical question: Who can act as a reference for 'Danish' genetic variation? The appendix stated:

> Individuals with an ethnic origin other than Danish can possibly be included according to the proportion in which they are found in the population. Yet it is estimated that a reference genome should be homogeneous and would not benefit greatly from the inclusion of ethnic groups with relatively few individuals. However, it [the reference genome] could be supplemented by seeking genetic information about these groups in other countries' national biobank projects.

As such, 'individuals with an ethnic origin other than Danish' are seen to impose an unacceptable genetic heterogeneity onto the Danish reference genome, and thus 'contaminate' its homogeneity if included.

A homogeneous Danish reference genome population as proposed in the appendix draws territorial boundaries—or 'genomic borders' (Svendsen, 2023)—up to which legitimate claims about genetic sameness and difference, as well as uniqueness, can be made through notions of biographical-territorial origin (Tarkkala & Tupasela, 2018; Tupasela & Tamminen, 2015). Such reference genome thus constitutes another example of techno-scientific 'geolocation'. According to Tupasela (2021), geolocation 'forms the basis of the development of criteria for inclusion and exclusion of certain groups from a geographic area,' thereby connecting ancestry and belonging to the spatial and temporal location of the nation through 'a common notion of origin and homogeneity' (p. 145). Like other national genome projects, the proposed reference genome population

mobilizes the nation-state border of Denmark 'to delineate the boundaries of a putatively biological population' (Burton, 2021, p. 255), enacting what it means and takes to be Danish as a matter of linear continuity and reproductive purity across generations within Danish territory (see Oikkonen, 2018, p. 190). Studying population genetic research in Finland, Tupasela has analysed and described similar discussions and practices of selecting who can represent Finnish heritage. With the term 'genetic romanticism', he demonstrates how genetic research practices informed by notions of genetic and cultural homogeneity form powerful narratives of national unity and origin (Tupasela, 2016). The community of 'Danish patients' demarcated by the reference genome population as proposed by the Research Committee is not universally constituted by all individuals with access to public healthcare services, as was the case with the patient genome population. This tethering of genomes (Hinterberger & Porter, 2015), and thus people, to territory, does not only demarcate 'Danish patients' as an exclusive community of ethnic Danes. The politics of exclusion also stratifies the relations between individuals and state into those who do and those who do not count as the subjects of state investment and commitment.

Tethering individual to state and state to individual: 'Danish patients' as an exclusive community

In the committee meeting in March 2019, one member inquired about the clinical value of the reference genome, asking the bioinformatician and other committee members more broadly about how the reference genome was to be used in the healthcare system. The authors of the already published Danish reference genome (Maretty et al., 2017) and members of the DNGC's Research Committee argued that a regional reference genome will enhance patient care by improving the clinical interpretation of genetic variants. Yet, in 2018, Gjødsbøl interviewed a laboratory analyst whose job it is to identify and interpret disease-causing genetic variation in patients with hereditary heart disease. When asked about the value of a Danish reference genome, he explained that he and his colleagues do not use or expect to use it in their work:

> The Danish [reference] genome … well … it exists …. What you use [in the clinic] is the international consensus. You don't refer to it [the Danish reference genome]. If you write an article, you have to refer to the international standard for people in other countries to be able to use it. The diseases we're looking into are so rare in a Danish context, so if we didn't look internationally, our knowledge would be incredibly limited. So, this [genomics] is a worldwide field, and we have to take in the world, we cannot limit ourselves by the Danish border. That's a mistaken belief. We're too small for that, we have to accept that. Otherwise, we should've been better at expanding territories at the time of King Christian the Fourth [in the seventeenth century]. … We've patients coming from all over the world, so we don't really care if the reference genome includes 15 generations from the moors of [the Danish region] Jutland if we're interested in the troops of Napoleon who came through Southern Jutland, you see? [Laughing] Then it's the French set-up, we might prefer. (Laboratory analyst)

Questioning the significance currently attached to genetic differences among national population isolates in biomedical research, the laboratory analyst problematized the

clinical value of the reference genome due to the small population of Denmark and the disproportion between the genomic population and its corresponding community of Danish patients. For him, a reference genome population composed of genetically homogeneous ethnic Danes does not correspond to the multi-ethnic character, ancestry, and thus genetic make-up of Danish patients requesting diagnosis and treatment in the clinic. Therefore, genomic populations should not be demarcated along the territorial lines of nation-states, but transcend geographical borders to accrue clinical value and usefulness.

Curated through a politics of exclusion, the envisioned reference genome population is a classic example of how population genetic research both draws upon and reifies notions of ethnicity, origin, and race. In so doing, it enacts a community defined by nationality and a historical 'conception of the people as an immobile, sedentary, and enclosed body politic within a territory' (Isin, 2018, cited in Cakici et al., 2020, pp. 200–201). In contrast to the patient genome population, which renders everyone with access to Danish healthcare eligible for inclusion, a genetically homogenous reference genome population would break with the universal approach to the community of 'Danish patients', in which every individual with access to the welfare state's healthcare services contributes and gains benefits. Demarcating an exclusive community in which ethnic Danes equal 'Danish patients', the reference genome population proposed by the Research Committee stratifies patients into two categories *within* the inclusive collective of the welfare state: ethnic Danes to whom the state is fully responsible and committed through investments in research and care, and non-ethnic Danes whose future quality of treatment will depend upon the existence of regional reference genomes in their countries of origin.

Populations, communities, and citizenship in precision medicine

At the time of writing (April 2024), the patient genome population in the DNGC has accumulated 29,511 genomes (The Danish National Genome Center, 2024). This number is increasing because a total of 17 different patient groups are now eligible for WGS within public healthcare (The Danish National Genome Center, 2022). The reference genome, however, remains an imagined population. So far, the DNGC has thus prioritized building the patient genome population, aiming to improve the care for a universal community of Danish patients. From a conversation between Gjødsbøl, Svendsen, and one of the DNGC's officials, we know that efforts are still being made to realize the Danish reference genome as part of Denmark's contribution to the European initiative, 'The Genome of Europe' (The Genome of Europe, 2023). The question of how to curate a population representing 'Danish genetic variation' remains practically, scientifically and ethically challenging. Yet as of April 2024, the management of the DNGC has abandoned the idea of a genetically homogeneous reference genome population of ethnic Danes, seeking out ways to curate the population that better account for the multi-ethnic population of Denmark. Although no informant expressed it directly, our impression is that besides the delicate issue of potential discrimination, there is also a problem to do

with the gap between clinic and research: in practice the Danish reference genome will be more useful for research than clinical care because of limited knowledge and clinical actionability of the genome. In other words, the DNGC's reference genome population seems to be caught between the political promises of its value for biomedical research and its lack of clinical usefulness for Danish patients in the present (Gjødsbøl et al., 2021).

This tension is not unique to Denmark. As pointed out earlier, the DNGC is not only collecting and curating genomic data because of its potential to advance the health of the Danish population, but also because of its presumed value in a global health data market. In other words, precision medicine, and its demand for data and data infrastructures, is becoming a crucial arena for the configuration and redefinition of the mutually binding state-citizen relations, and thus social citizenship, in the welfare state (Hvinden & Johansson, 2007; Johansson & Hvinden, 2005). In a recent article about the multiplying uses and purposes of health data collection in Finland, Snell et al. (2023) demonstrate that the logics of the welfare state and that of a data-driven health economy stand in a paradoxical relationship, challenging the social contract of the welfare state relying on solidarity. On the one hand, they argue, 'being part of the data economy is dependent on the welfare state practices and solidarity that rests upon reciprocal virtuous circles between state and the citizens'. On the other hand, 'the logic of data-driven health economy dismantles the existing bases of solidarity since data extraction is focused on the generation of private profit' (Snell et al., 2023, p. 2). In a data economy, the authors note, it is unclear what obligations and rights individual citizens hold in relation to their own health data, and who reaps the benefits of data-intensive businesses. With their concept of solidarization, they demonstrate how people, in the name of solidarity, are expected to accept the collection and use of their health data as part of their citizenship. They ask whether solidarization might result in conditional citizenship in case only those who accept solidarization will be entitled to services (Snell et al., 2023).

As health data increasingly become sourced to serve commercial and economic agendas in Denmark as well, we recognize similar challenges and appreciate this timely question. Yet, our analysis provides a different perspective to the question of conditional citizenship, namely that the curation of national data populations might both *enable* and *deprive* individuals from entering into solidary relationships with their fellow citizens and 'reciprocal and virtuous' relationships with the welfare state. Whereas the politics of inclusion curating the patient genome population enacts a universal community of Danish patients that enables citizens to enter into reciprocal relationships with the state, the politics of exclusion curating the proposed reference genome population enacts a selected, privileged community that would deprive citizens of non-ethnic decent of entering such relationships of obligation and commitment. While the strategies employed to curate genomic populations may well be grounded in scientific and statistical arguments, in the modern state, statistical descriptions actively construct biological and social life by providing grounds for political action (Cruz, 2017; Desrosiéres, 1994). As we have shown, the criteria for inclusion and exclusion applied to curate national data populations condition and might differentiate citizens' possibilities to enact 'health citizenship' (Jauho & Helén, 2022). As the flagship of Danish precision medicine, the DNGC seeks to enhance the prevention, diagnostics, and treatment of Danish patients, yet the

patient genome population and the proposed reference genome population do not configure this community, and the state's responsibility and commitments towards it, consistently. The shifting politics of inclusion and exclusion thus embody two different versions of the individual and the Danish state: The patient genome population configures the patient as a healthcare service user in need of care and the state as a welfare state, whereas a reference genome population of ethnic Danes configures the patient as a national subject and the state as a territorial state.

To be clear, we do not question that a genetically homogeneous population might offer an effective means to detect genetic variation of significance, just as we do not claim that the DNGC's officials intend to stratify the social contract between individuals and the state along the lines of ethnicity. Yet, as Oikkonen (2018, pp. 212–213) has argued, 'politics does not need to be conscious in order to have significant consequences. The geneticization of communal belonging invokes an array of assumptions about race, nation, reproduction, and gender that may not be intended by the speaker.' What we stress here is that the population objects curated through 'methodological nationalism'—what Burton (2021, p. 7) poignantly describes as an uncontested acceptance of the nation-state and its borders as the natural unit of analysis in population genetics—engender not only categories of race, ethnicity, and origin, but also moral and political obligation. In our case, a genetically homogeneous Danish reference genome would constitute a move towards grounding citizenship in biology, prescribing a moral continuity and politics of belonging between ethnic Danes, the nation-state, and its territory (see Svendsen & Navne, 2023). Its realization would mark a development towards conditional health citizenship, disregarding the principle embodied in the DNGC's patient genome population and considered fundamental to Danish welfare society: universal access and equal opportunities for everyone in the community of healthcare-seeking individuals.

Conclusion

Taking Denmark's most significant national precision medicine initiative as our case study, we have shown how different and even contradictory strategies for population curation co-existed within the same techno-scientific site, and how different inclusion criteria result in divergent configurations of who constitutes 'Danish patients'. These insights call for stringent scholarly attention to what kinds of communities national genomic populations imagine and enact, and how the resulting population objects potentially reorganize normative relations of obligations and commitments between citizens and the state. Our investigation of the DNGC's inclusion criteria illuminates what is easily concealed in scientific practices and in discussions about how to create the most valuable genomic populations for researchers, clinicians, and state officials: namely that epistemological practices have ontological ramifications for citizen-state relationships. With the concept of population curation, we have drawn into focus how the establishment of national genome databases is not only about collecting data and categorizing people, but also implies normative relations between individuals and the state through the mutual construction of data populations and their corresponding communities.

We have studied the politico-administrative negotiations of the inclusion criteria defining who is eligible to become a data point in the DNGC's genomic populations. What needs to be researched from here is how population curation happens on the ground when patients enter the clinic to seek healthcare (see Dam et al., 2022; Skovgaard & Svendsen, 2023). Although many patient groups are now eligible for WGS in the context of publicly funded healthcare, due to resource constraints there is an upper limit to how many patients can be offered advanced genetic analysis. This means that the clinic is a space for local, subjective selection processes, as clinicians decide which patients are offered WGS as part of their treatment and thus who enters the DNGC's patient genome population. In practice, disempowered and dispossessed populations are often excluded from research populations because they are considered 'hard-to-reach,' leading to inequalities in health research, health, and healthcare (Krieger, 2012, p. 666). From our ethnographic engagements in Danish clinics, we know that this problem pertains to the Danish context as well. For example, clinicians may consider some patients' Danish language proficiencies insufficient to be able to understand information about WGS and the possible implications of advanced genetic analysis. In other words, the patient genome population might, in practice, come near to being a genetically homogeneous population through local selection practices privileging the inclusion of ethnic Danes who are easy to reach (Krieger, 2012). This will not occur because of an epistemological or methodological quest for genetic homogeneity, but because of pragmatic choices about how to do clinical research in the least complicated and most effective way, and because of clinicians' moral concerns for the individual seeking healthcare who needs to be informed and to give consent to become a research subject.

The challenges in thinking critically about populations are not only conceptual, but also political. This is 'because these ideas necessarily engage with issues involving not only the distribution of people but also the distribution of power and property and the social relationships that bind individuals and populations, for good and for bad' (Krieger, 2011, cited in Krieger, 2012, p. 668). Indeed, our analysis of population curation in Danish precision medicine adds nuance to some of the critiques of the concept of population. Social science scholars have poignantly shown how the definition and management of human populations have had troubling and even violent effects (see Appadurai, 1993; Clarke, 2018; Rabinow & Rose, 2006). In her analysis of what she terms the economization of life, Murphy (2018) shows how the government of population as 'a simple quantification of mass' to be curbed (p. 104) 'designates poor people as a form of human "waste," better for the world to be without' (p. 106). Consequently, she sees no other option but to abandon the concept altogether (see also Murphy, 2017). While we strongly support—and aim to contribute to—a continuous critique of how (data) populations are managed, and with what effects, we agree with Swanson (2019) that social scientists have failed to investigate the positive effects of population concepts and numerical descriptions. As we have shown, eligibility as a data point in national data populations is crucial to social and health citizenship: for the individual in the welfare state, being included in a genome population acts as means to become tethered to the state, and thus to be made legible as part of the community for which the state is responsible and committed to care for.

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