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Strategies on personalized medicine and the power of the imagined public

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Personalized medicine has become a central focus of health and innovation policies in many countries. It is a complex policy field which, in the pursuit of both health and wealth, brings together technology, new data use, and medical care. The aim of this paper is to analyze how the notion of personalized medicine has evolved, and what publics are implied in the political mobilization of the concept. We answer these questions based on a document analysis of Danish strategy papers in the period 2014–2021 and expert interviews. We identify different strategy actors driving the process, shifts in topics during the strategy process, as well as different imaginaries of the public. We argue that each group of strategy actors act with a particular public in mind and that these influence how personalized medicine is envisioned. If the relationship between strategy development and the imagined publics remains unknown, it can pose a democratic problem.

Keywords: personalized medicine; imagined public; health policy; strategy development; document analyze; public trust; welfare state; data collection

Introduction

Across the world, personalized medicine has become a central policy focus during the last two decades (Reardon 2017; Tupasela 2021). With the aim of targeting diagnostics, prevention and treatment to individuals, personalized medicine strategies and policies concern, for example, the governance of genomics, biobanks, drug development and data security. Personalized medicine involves many actors from both private and public sectors and it relates to citizens in many ways – as patients, data sources, and taxpayers. In addition, it cuts across several policy arenas such as health, research, innovation and economic policy (Heta Tarkkala, Helén, and Snell 2019). What counts as personalized medicine
is still debated and reframed both in the academic literature (Erikainen and Chan 2019; Prainsack 2017; Tutton 2012) and in the policy field (Australian Health Ministers’ Advisory Council 2017; General Secretariat of the Council 2015; Health 2016; Keogh 2015). Even the term personalized medicine has been debated, and there are other overlapping concepts such as stratified, precision and P4 medicine that are often used interchangeably although they have slightly different emphasis (Erikainen and Chan 2019). Our study is located in Denmark, and thus we use the most common term in this country, which is personalized medicine.

In the following, we set out to understand how the complex notion of personalized medicine has evolved over time in the Danish strategy process. In our investigation of policy documents, strategy papers and the policy processes of implementing personalized medicine in Denmark, we observed that some topics are very central at specific points in time and in specific documents and at other times they are ignored, forgotten, deemed irrelevant or perceived as subordinated (Jensen and Svendsen 2021). This spurred an interest in how to understand these fluctuations. All policy documents included in our study articulate the population as both a resource for personalized medicine and recipients of its products and services. In light of citizens central and dual role, we were intrigued by the way the actors behind the documents imagined and perceived these citizens. Therefore, the aim of this paper is to analyze how the notion of personalized medicine evolves over time through changes in topics and arguments, how the different policy actors imagine the citizens and the association between these two phenomena.

To analyze this, we found inspiration in the concept of imagined public introduced by scholars in environmental research, who use the concept to understand the different dynamics in a policy process (Barnett et al. 2010; Rodhouse et al. 2021; Walker et al. 2010). We show that different imagined publics influence which groups of citizens the policies address, and also which groups they do not address and who thereby are more or less excluded from taking part in the realization of personalized medicine. By making the imagined publics explicit, we are able to understand the evolution of the notion of personalized medicine, and to understand how the actions of the imagined publics may have consequences for the version of personalized medicine implemented in an actual healthcare system. We argue that if imagined publics remain unacknowledged, we fail to realize the main driver of the development of strategies and policies.

**Imagined publics**

In social science, life science policies – including policies on genetics, personalized medicine and health data governance – have often been investigated with discursive approaches (Erikainen and Chan 2019; Jones and Salter 2003; Martin and Turkmendag 2021; Webster 2005). This has also been the case in a Danish context where (Burau et al. 2021; Deleuran Terkildsen et al. 2020) studies show that
discourses shape the direction of innovation and that competing discourses about technological futures and narratives sometimes overlap, sometimes in powerful discord with each other (Burau et al. 2021; Deleuran Terkildsen et al. 2020). The development of personalized medicine is, for example, described as “… a process characterized by diverse sub-discourses which in combination make up a special version of personalized medicine” (Deleuran Terkildsen et al. 2020).

In highlighting the performative aspect of expectations, the theoretical work within sociology of expectations e.g. (Brown and Michael 2003; Hoeyer 2019) and the theory of sociotechnical imaginaries e.g. (Jasanoff and Kim 2015; Jensen and Svendsen 2021; Heta Tarkkala, Helén, and Snell 2019) have uncovered how political visions not only articulate a possible future, but in themselves drive the technology development and pave its way into societal institutions. While these studies bring to the fore the coproduction of technology and political vision, they do not to any great extent pay attention to the particular notions of individual citizens or groups of citizens in political visions and policy processes.

Other scholars have investigated the imaginaries of publics in scientific practices and public engagement. Based on a UK study of imagined publics from the Second World War and onwards, Ian Welsh and Brian Wynne describe a development from a passive compliant imagined public to an imagined public who resists what is best for them due to their limited scientific understanding, ending with a public imagined to be a threat to science, as it does not comprehend the need for scientific supported commercial innovation in the global competition (Welsh and Wynne 2013). In a later study, Rommeteveit and Wynne point out that imagined publics are closely linked to political and economic agendas (Rommeteveit and Wynne 2017). In the following, we take inspiration from this literature in combination with studies of biobanking and biomedicine, showing that certain imaginations of publics are utilized to recruit biobank participants, and to brand national research, infrastructures and the population itself (Busby and Martin 2006; Tarkkala and Tupasela 2018; Tupasela 2021; 2022). For example, Gottweis et al. point out that a public only exists when someone or a group of citizens are interested in something. Thus, biobanks start to imagine a public when they experience an interest from citizens in their work (Gottweis 2002).

In environmental research, the concept of “imagined publics” is used to describe, conceptualize and theorize the involvement of the public in strategy processes and controversies. A common reference point for the concept of imagined publics is a paper by Maranta et al., where the authors outline the concept of the “Imagined Lay Person” (ILP), which is introduced to shed light on the implicit assumptions of the public described in literature within Public Understanding of Science (PUS) research (Maranta, Michael, and Pohl 2003). Maranta and colleagues make the point that ILPs act as functional constructions for experts in their knowledge production and that they are not a sociologically comprehensive
representation of lay persons, but a way of ascribing epistemic and functional competences to lay persons. ILPs are often ascribed a limited number of competences, even though the collectives they represent feature all kinds of competences (Maranta, Michael, and Pohl 2003). Since Maranta and colleagues’ first article on the topic, ILP has evolved into the concept of imagined publics. Rodhous et al. define imagined publics as: “...subjective social representations that build upon all sorts of assumptions and beliefs about the identities, abilities, knowledge, behaviors, and responsibilities of a particular group of people” (Rodhouse et al. 2021, 2). Imagined publics appear as fairly static knowledge schemes, which can be drawn upon whenever a representation for “the public” is needed. In this way, imagined publics are used to predict and counter the public reactions and positions on proposed politics and projects (Rodhouse et al. 2021). It is through the identification of different populations that regulatory interventions can be initiated (Ruppert 2011). Previous research has suggested that the imagined public is more significant for the development of a technology than the public it is supposed to represent (Rodhouse et al. 2021; Walker et al. 2010). Consequently, the imagined public becomes an actor with agency and political significance (Walker et al. 2010). In strategy processes, the public is always present in an abstract form, and influential on the development of a policy (Gisle 2018). Moreover, different imagined publics can co-exist, apparently representing the same group of people (Rodhouse et al. 2021).

In the present article, we apply the concept of imagined publics to the policy fields of personalized medicine. Where research in the environmental field has previously used the concept to analyze the involvement processes of the public in governance work and policy processes, we use it to contextualize the changes in argumentation and topics discussed in the different phases of the strategy process. “Imagined publics” as a concept helps us understand the changes in topics and argumentation and paves the way for uncovering how different strategy actors draw on different imagined publics, and as a consequence envision different versions of personalized medicine. Thereby the concept helps to understand how perceptions of publics are influential on policy and strategy outcome. In the Danish strategy papers, the imagined public is both understood as a passive research subject, a patient with the goal of receiving treatment, and an active citizen with the capacity to push back.

The Danish context
To set the scene for our analysis of the policy process, we will briefly introduce the Danish context. Denmark is a high-income country, with around 5.7 million inhabitants. Danish society is based on an all-embracing welfare state model, which co-exists with a free market economy. This means that the Danish healthcare system is primarily publicly funded through the redistribution of wealth through taxation, and is part of a welfare state offering all kinds of welfare services.
throughout the life of a Danish citizen. Denmark has five regions whose primary responsibility is to run hospitals and other healthcare services. The regions are governed by a democratically elected regional council, and they negotiate an annual budget with the national government. An umbrella organization called “Danish Regions” represents the five regions in political processes.

Like in other Nordic countries, there is a close relationship between the generation and collection of data and the development of welfare policies in Denmark. Every interaction with public institutions, including many private institutions, create data about the individual which become connected to the individual by a personal identification number. This means that in the welfare state, citizens’ interaction with state institutions produces massive amounts of data (Tupasela 2021), an outcome which has been framed as a natural part of state-citizen relationships: citizens fund healthcare services by paying taxes in exchange for access to these services. The data generated in this relationship comprise a collective good to be used for quality development of welfare services and for research (Bauer 2014; Hoeyer, Bauer, and Pickersgill 2019).

The development of personalized medicine in Denmark takes place in dialogue with similar developments in the Nordic Countries and the European Union. Crucial initiatives on the European scene are the visions of a European Health Data Space (https://www.european-health-data-space.com/) and the 1000,000 Genomes Project in the UK (https://www.genomicsengland.co.uk/initiatives/100000-genomes-project), which Danish stakeholders often highlight as an inspirational model for how to make genomics part of routine healthcare and enhance personalized medicine. Also, as a member of the International Consortium for Personalised Medicine (ICPerMed), Denmark supports research and implantation activities in Europe and internationally, with the aim of supporting and aligning research, funding and implementation of personalized medicine (https://www.icpermed.eu/index.php).

In tandem with these international initiatives, the Danish parliament decided, in 2018, to establish the National Genome Center as a key institution in a national infrastructure for the collection and storage of all information from genetic testing in the Danish healthcare system, thereby creating a huge database of genetic information. The proposal generated an intense public debate about privacy issues and the state’s intentions of collecting and storing all these data (Skovgaard and Hoeyer 2022). In the debate, the generation and collection of population health data appeared as a somewhat new – and worrying – endeavor in the welfare state (Svendsen and Navne 2022), despite data generation having always taken place since the establishment of welfare state institutions in the first half of the twentyish century. The debate gave voice to worried citizens questioning well-established data collection procedures, as these were coming to be seen as serving new purposes in a digitalized and data-intensive society.
Data collection and analysis process

To investigate the evolvement of Danish policy process in connection to personalized medicine, we have employed a qualitative study containing a document analysis and semi-structured interviews with policy actors. For the document analysis, we studied the relevant Danish policy documents and strategy papers from the first descriptions of a national initiative on personalized medicine (2014) to the latest updated national strategy on personalized medicine (2021). We have included all strategy documents specifically focusing on personalized medicine. Given our specific interest in the concept of personalized medicine, we have excluded health data and life sciences strategy documents which do not explicitly focus on personalized medicine. All the documents included in our study are available on public platforms. Interview participants were helpful in identifying relevant documents. For an overview of included documents see Table 1.

The document analysis was accomplished by applying a Thematic Analysis approach, where we read through and coded each document according to the topics and arguments put forward (Braun and Clarke 2006; 2019). We did this in an explorative way without in advance restricting ourselves to specific themes. The coded themes were then worked through by the first and last author to clarify the meanings of the themes, and some themes were collapsed because of overlapping content. The analysis process is inspired by what Coffey and Atkinson have named “the coding and retrieving strategy”. Using this strategy has three objectives: (1) to identify relevant phenomena, (2) to gather examples of the phenomena and (3) to analyse these phenomena so as to identify similarities, differences, patterns and structures (Coffey and Atkinson 1996, 29). Nvivo software was used to structure and arrange the coding process. The process resulted in 15 topics/arguments, which can be examined in Table 2.

We divided the strategy process into three time periods, each period defined by the strategy actors driving the strategy process. This division is of course not clear-cut as all actors are involved in all periods, but the three time periods indicate a shift in which actors were the main drivers. Three groups of strategy actors were identified: (1) “Practitioners”, covering biomedical researchers and working physicians, bioinformatics researchers, and Deans from the health faculties; (2) Regional political actors, including Danish Regions, regional politicians and heads of corporate management in the five regions; and (3) National political actors, including national politicians and government officers from several departments.

The interview material in the present study is composed of 26 interviews with 28 interviewees. Interviewees represent research physicians at university hospitals (6), other researchers (4), Deans of health faculties from Danish universities (3), head of corporate management in the five regions (5), chairpersons from the five regional councils (5), employees from the Ministry of Health (2) and
Table 1. The included strategy documents.

<table>
<thead>
<tr>
<th>Title and year</th>
<th>Aim of the document</th>
</tr>
</thead>
<tbody>
<tr>
<td>A national Danish initiative on precision medicine and individualized medicine</td>
<td>To present a brief memorandum on the establishment of a national Danish initiative on precision medicine</td>
</tr>
<tr>
<td>Published in 2014 by deans of the health faculties</td>
<td></td>
</tr>
<tr>
<td>A national Danish initiative on precision medicine and individualized medicine</td>
<td>To present the effects of implementing genomic medicine in clinical work at hospitals and the infrastructure and organization needed to realize this.</td>
</tr>
<tr>
<td>Published in 2014 by deans of the health faculties</td>
<td></td>
</tr>
<tr>
<td>Personalized medicine and individualized treatment – proposal for a collective Danish effort</td>
<td>To present a proposal for a collective Danish effort on personalized medicine.</td>
</tr>
<tr>
<td>Published in 2015 by the five regions, Danish Regions (umbrella organization for the five regions), Aarhus University, University of Copenhagen, Aalborg University, University of South Denmark, Danish Patients (interest organization)</td>
<td></td>
</tr>
<tr>
<td>Denmark should focus on personalized medicine Published in 2015 – A press release from the Danish Government and Danish Regions</td>
<td>To state that the Danish Government and the Danish Regions have allocated 5 million Danish krone to an initial analysis on the future of personalized medicine</td>
</tr>
<tr>
<td>Plan of action for personalized medicine Published in 2015 by Danish Regions</td>
<td>To provide a brief description in plain language of personalized medicine and the regions’ thoughts on personalized medicine</td>
</tr>
<tr>
<td>Danes’ thoughts on and attitudes towards personalized medicine and genetic testing Published in 2016 by The Danish Ministry of Health, Danish Regions</td>
<td>To investigate Danes’ attitudes towards personalized medicine by means of a questionnaire and two public meetings.</td>
</tr>
<tr>
<td>Terms of reference according to an initial analysis on personalized medicine Published in 2016 by The Danish Ministry of Health</td>
<td>To describe the terms for the initial analysis on personalized medicine</td>
</tr>
<tr>
<td>Reporting from the reference group on personalized medicine – an initial analysis Published in 2016 by the reference group</td>
<td>To present an initial analysis on the implications of implementing a larger national programme for personalized medicine. Describes different scenarios for implementing personalized medicine.</td>
</tr>
<tr>
<td>Analysis of personalized medicine – completed for Danish Regions Published in 2016 by Damvad Analytics</td>
<td>To present a mapping of Danish business operators engaged in personalized medicine. To analyse – in comparison with other countries – the strength of Danish research engaged with personalized medicine.</td>
</tr>
<tr>
<td>Mapping of international experiences with personalized medicine</td>
<td>To inspire the drawing up of a national strategy on personalized medicine.</td>
</tr>
</tbody>
</table>
employees in Danish Regions (2). The interviews were conducted as part of an investigation of the implementation of personalized medicine in Denmark on a political administrative level. In the present article, interviews are used with a more specific purpose, namely, identifying statements about the public. The interviews were conducted in retrospect, meaning that in our conversations with strategy actors, they looked back on the strategy and policy process and reflected on the
present initiatives. The persons interviewed had all been part of the strategy process even though some were more central than others. First, the first author coded the documents and interviews, looking for descriptions of “publics”. Second, the first and last author went through these codes to identify themes describing the different imagined publics. The imagined publics thus identified are described in the sections below.

<table>
<thead>
<tr>
<th>Themes discussed in the strategy papers</th>
<th>Time period (Policy actors)</th>
<th>2014–2015 (Practitioners, researchers: physicians, bioinformatics, deans)</th>
<th>2015–2018 (Practitioners and regional political actors)</th>
<th>2018–2021 (Regional political actors, national political actors)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The establishment of a Danish national reference genome</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research is important in the realization of PM</td>
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</tr>
<tr>
<td>Prevention is an important part of PM</td>
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<tr>
<td>Conventional treatment is less efficient than PM</td>
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<tr>
<td>Public-private collaboration is important for developing PM</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>International collaboration is important for developing PM</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>PM ensure growth potential for industry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalized medicine is a revolution</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Denmark is in a unique position for developing PM</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus should be on treatment and not research and prevention</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PM involves ethical dilemmas important for citizens</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data security/privacy is one of the most important issues in PM</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Public trust in public institutions is important to maintain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public institutions can best handle PM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PM is more efficient than conventional treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private actors are important for developing PM</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

A green square indicates that the topic is discussed a lot, a yellow square indicates that the topic is discussed somewhat, a red square indicates that the topic is almost not discussed.
To sum up, the document analysis revealed different topics and arguments emerging and disappearing through the three time periods. We then re-analyzed this material to uncover the representation of publics in relation to the identified topics and arguments. The interview material helped us understand the political context of the documents and see connections between specific groups of strategy actors and the publics they imagined.

Ethical approval

According to Danish legislation, research using questionnaires and interviews that do not involve human biological material (§14(2) of the Committee Act) interview studies are exempt from approval from the Committee on Health Research Ethics (https://en.nvk.dk/how-to-notify/what-to-notify). Informed oral consent was obtained and recorded prior to all interviews.

Imagined publics underlying official strategies on personalized medicine

In the following, we present our empirical analysis structured according to the three time periods. We describe the main discussion topics and arguments in each time period together with the identified imagined publics.

Time period 1: launching the idea of personalized medicine (2014–2015)

The key strategy actors in this first time period were researchers at universities and university hospitals, and the deans from health faculties at five Danish universities. For these actors, the main focus is to raise political awareness about personalized medicine as a research area which is to be developed in close connection to the public healthcare system and to attract funding for this endeavor. The end goal is to establish a research programme in personalized medicine for the benefit of future patients.

In 2014, researchers and deans at universities and researchers at university hospitals begin to draw up documents about introducing personalized medicine in Denmark. The faculties of health sciences at Danish universities have an ongoing dialogue with heads of corporate management in the regions to coordinate research and development at the hospitals and the universities.

As Table 2 shows, deans and researchers emphasize the needs and importance of research when drawing the lines for a national initiative on personalized medicine. For them, it is important that the strategy enables well-functioning structures for conducting research in the field of personalized medicine. A strategy paper on a common initiative for personalized medicine from this time period states:

A project like this will support many Danish research areas, which connect knowledge about the genome to Danish population registers and clinical parameters. These activities will create extensive exposure for Danish research and contribute to securing Denmark’s position in the knowledge society within a sector which is critical for
[the] Danish economy (Personalized medicine and individualized treatment – proposal for a unified Danish effort 2015).

The research in focus is research which holds great potential for Danish society, the economy, and future treatment of patients. With inspiration from the 100,000 genome project at Genomics England, the ambition is to collect whole genomes from 100,000 Danes to establish a reference genome with the long-term ambition of including the full population in this biobank. It is, for example, expressed in the following extract:

The infrastructure should enable 100,000 Danes to be offered the opportunity to be part of a national genome biobank in preparation for establishing a unique foundation for research in future prevention and treatment options (Personalized medicine and individualized treatment – proposal for a unified Danish effort 2015).

For the researchers, this strategy and the ambitions for the research agenda can only be realized through collaboration with international partners and through public-private partnerships. In another document from this period, it is stated that a national initiative on personalized medicine will benefit Danish industry, especially the strong Danish pharmaceutical industry, and have the potential to create growth within the private sector. As one report states:

This development will have unprecedented commercial potential consisting of new medical products, which in the future will be priced according to their effectiveness in treatment. Knowledge from the massive amount of data generated across the population will lead to new types of companies at the interface of health science and IT (A national Danish initiative on precision medicine and individualized medicine – A 2014).

The two main policy documents from this period (A national Danish initiative on precision medicine and individualized medicine (B), 2014; Personalized medicine and individualized treatment – proposal for a unified Danish effort, 2015) are produced mainly by researchers and deans. These documents picture an imagined public, which consists of patients and/or research subjects who take an interest in being treated through personalized medicine and/or being willing to contribute to future treatment. Not only are the general public perceived as a resource for the realization of personalized medicine and as receivers of personalized medicine; the public are also seen as trusting researchers and health professionals, and as being willing to contribute with their data without concerns regarding collection, storage and use of data. In our interviews with researchers and deans from this time period, they repeatedly take the position that citizens are already so entangled with welfare state services and hand over so much private information to the state, that the state’s storing of genomic information will not worry them.

When you consider the amount of information we report to the Danish Customs and Tax Administration about marital status, our salary, et cetera, it’s a lot of information we report to public institutions without being nervous about it. I’m in no way
nervous about this (the collection of genetic data) or misuse of data (Researcher and physician 1).

The reciprocity of citizens receiving services and public institutions registering and using data to improve welfare services is perceived, by the central actors in this period, as being part of the reciprocity between state and citizens, anchoring life and living in a welfare state. Despite these citizen-state relationships in the welfare state, the researchers and deans articulate a potential concern among citizens. They imagine that some people might be worried and skeptical about data collection if they themselves are not part of genetic counselling or treatment. But researchers and deans expect that once the citizen becomes patient, most of this worry and skepticism will disappear.

If you look at patients’ and citizens’ motives to hand over data, they are very different. As a patient you say: Take samples. Do whatever you want with them. Find out what to do for me and the ones who have the same condition as me. As a citizen you think: What do you want with it (health data/genetic information)? What are you going to use it for? (Dean 2)

In interviews, the strategy actors of this period expressed that the worry and skepticism among citizens can be laid to rest by the right amount of information, at the right time, to ensure a feeling of transparency. A researcher expresses this understanding in the following quotation:

I understand that one could be worried, but I think information is important, to try to inform the public as much as possible, what all this is, and how are they going to be treated. I think that the National Genome Center is doing a very good job, putting all sorts of information on their website. And we’re trying to do the same. (Researcher 3)

In the scholarly literature, this portrait of public attitudes is often referred to as a deficit model, where skepticism or negative responses to research are seen as consequences of lack of public knowledge about research and research processes. In this perception, a lack of knowledge can lead to resistance towards new technology and science (Am, Solbu, and Sorensen 2021; Barnett et al. 2010).

Topics not mentioned in the documents from this time period are the issues of data security or privacy, the need to control and implement personalized medicine in the public healthcare system, and issues about public trust in public institutions as a critical parameter for the success of personalized medicine. The “missing” topics indicate that the researchers are not concerned about the issue of trust. A fair number of the researchers do not make explicit references to a public. This absence tells us that they take as self-evident the various publics’ willingness to participate. Although they know individual persons/patients who may be skeptical, they do not expect skepticism from the majority. They see citizens and patients as trusting researchers and health professionals and as being positive towards new treatment options.

In the second time period, the key strategy actors were practitioners active in research from the university hospitals, politicians from the regional councils, heads of corporate management in the five regions, and members of staff from Danish Regions. In policy documents, these actors continue to focus on attracting funding to personalized medicine and generating interest in the field by involving national politicians. Personalized medicine is presented not so much as a research area, but as a new treatment paradigm. Personalized medicine as a new treatment paradigm is taken to be “the future”, and the task at hand is to convince the national politicians of this. Again, citizens are expected to – simultaneously – enable the realization of personalized medicine and benefit from it.

In the documents in this time period, we have observed a shift in focus which makes it different from the previous time period. Emphasis shifts from prevention and treatment to an almost exclusive focus on treatment. Accordingly, research and the mapping of a national reference genome play a less central role than in the previous time period. For the first time, documents mention the ethical dilemmas concerning the collection, storage and use of patient and citizen data.

Hence, it is important to safeguard the security, health, integrity and right to self-determination of both research subjects and patients, at the same time safeguarding the development of the healthcare system for the benefit of patients, including the development of personalized medicine (Reporting from the reference group on personalized medicine – an initial analysis 2016).

Here, citizens’ integrity and right to self-determination are foregrounded. In contrast to the previous period, the policy documents mention and discuss citizens’ trust in public healthcare institutions. The logic put forward is that to make personalized medicine a reality, it needs to be located and developed within public healthcare because the citizens trust the public institutions’ abilities to handle the ethical dilemmas. The focus is very much on keeping personalized medicine within public institutions.

The development of personalized medicine is dependent on informing Danish patients and citizens about treatment and research. Transparency and dialogue with citizens are critical. Patients and citizens should be involved, and information, communication and involvement are critical activities (Personalized medicine for the benefit of patients 2016)

The text from the national strategy articulates the public as a central resource for the realization of personalized medicine. Moreover, public participation in the discussions on personalized medicine needs to be stated and facilitated. In the documents, personalized medicine is presented as a very complex system facing the challenge of responsibly taking care of data storage, protection and sharing. In the documents, strategy actors communicate that public institutions will take responsibility for these issues as they always take responsibility for their citizens.
The deficit model is not as strong in this time period as in the previous one, but still strategy actors communicate that rules, regulation and information should calm citizens and enable citizens to participate without hesitation. Strategy actors expect that citizens will support the implementation of personalized medicine, but the support needs to be cultivated continuously.

Even though the documents convey a strong focus on public institutions, including citizens’ trust in the collection, storage, and use of data in public institutions, they also acknowledge the benefits of public-private partnerships. For example, the national strategy on personalized medicine from 2017–2020 (Personalized medicine for the benefit of the patients 2016) says: “We see promising possibilities within public-private collaboration on new treatment options – and especially new medical products – for the benefit of the patients”.

The documents convey that regional politicians and heads of corporate management understand the imagined public as first and foremost a patient. The patient is imagined as finding it difficult to understand the consequences, pitfalls, and benefits; and in general, the information connected to the sequencing of the genome. Therefore, the imagined (patient) public are in need of guidance and assistance to navigate the difficult space of personalized medicine. This way of imagining the public places a great deal of responsibility on the strategy actors. They see it as their responsibility to guide patients in this paradigmatic change within healthcare services.

It can be difficult for a citizen to cope with the consequences of going through a genetic sequencing, and therefore I believe that as a public healthcare system we have a responsibility for giving thorough information to the patients before they go through a genetic sequencing (Head of Corporate Management in Region 5)

The regional politicians and heads of corporate management expect citizens to trust public institutions, in particular the public healthcare system, and thus see these institutions as the preferred actor to collect, store, and use genetic data and to provide guidance to patients within this field. Generally, the imagined public reflected in these statements are willing to share and use data, and anticipate that their data are used to advance their own treatment and the future of medicine.

I’m not afraid of it (the use of genetic information). In fact, I’m convinced that the Danes really want to participate in it, because it will raise the quality of our healthcare system and we can all be treated for far more diseases with better quality in the future (Director of region 2)

To sum up, in this time period, the public are seen as a resource for the realization of personalized medicine; and for this resource to be mobilized in legitimately and socially robust ways, the public need to have an active role in discussions about use and reuse of data. Hence, they are imagined to be a more active public than in time period 1. At the same time, policy actors see the public as in need of protection and guidance, in a field perceived as very complex. In contrast to time period 1, the documents do not discuss prevention and only briefly mention
private actors and potential international collaborations with researchers and companies.

**Time period 3: citizen support is critical (2018–2021)**

In the last period, the policy documents center on encouraging citizens to accept the idea of personalized medicine and support the National Genome Center as the infrastructure for the collection, storage, and use of data. The imagined public of the policy documents has changed from research subject (time period 1) and patient (time period 2) to citizen. This citizen is active, has the potential for active resistance, and takes an interest in debates about the use of private data, for example in connection with “big tech” companies and their use and misuse of health data. Thus, strategy actors are also concerned about debates on data misuse and its consequences for the implementation of personalized medicine.

The documents included from this time period have a strong focus on the ethical dilemmas related to collection, storage, and use of patient data. Therefore, they are also very much concerned about data security and data privacy, and keen to place the infrastructure of personalized medicine in public healthcare institutions. Citizens’ trust in public institutions is mentioned as strong, yet also as something which cannot be taken for granted. Thus, efforts are needed to retain public trust in order to make personalized medicine a success.

It is crucial for the trust in the Danish development of personalized medicine that the initiative rests on a widespread information effort as well as a solid ethical, legal and data security foundation. More knowledge must be created on an ongoing basis about ethical, legal and societal aspects connected to the commissioning of genome sequencing and personalized medicine in the healthcare system (Personalized medicine for the benefit of the patients 2020).

This text from the most recent national strategy on personalized medicine responds to issues raised in the public debate about the establishment of the National Genome Center. In addition, the national political actors, in the interviews, are pre-occupied with the general debate on data use and misuse, a debate which has been going on for some years in Denmark, originating from cases of data collection and data misuse within large tech companies. In response to these worries, an ethical committee and a citizen committee were established at the National Genome Center with the objective of highlighting ethical issues involved in personalized medicine. The national political actors depict a public which, in light of debates on data collection and data use, shows a growing mistrust in public institutions and their motives for collecting, storing, and using data on a national level. In an interview, an employee from the Danish Ministry of Health says:

“How do we keep and ensure the trust of citizens and patients? It is important that we are transparent and inform citizens and patients sufficiently, when we introduce these new genomic technologies. It’s to help the patients that we do this. It’s to help the
patients, which is also the focus in the strategy. It’s not to go out there and map all Danes’ genomes with all kinds of different purposes.” (employee from the Danish Ministry of Health, 2019).

Despite the restricted intentions of the Danish national strategy, policy actors still imagine a public which trusts public institutions more than private actors, when it comes to handling private data and information. The national political actors see public skepticism towards the National Genome Center as a result of citizens’ limited understanding of personalized medicine.

Similarly, to the previous time period, national strategy actors focus almost exclusively on personalized medicine in relation to treatment. Neither prevention nor research and the mapping of a national reference genome are giving much attention in the documents. Other topics not touched upon in the included documents are the possibility for public-private partnerships, the role of private actors in the field, the benefits and necessity of international collaboration, and the growth potential for private companies within the field of personalized medicine and genomics. The documents portray personalized medicine as an activity performed solely by public actors and located in public institutions.

Discussion

By analyzing Danish strategy papers and other central policy documents on personalized medicine, we have identified three time periods in the strategy- and policymaking process. In these three time periods, we have observed a pattern of different topics and arguments emerging and disappearing from the documents. Based on the documents included and the interviews of actors involved in the strategic work of personalized medicine, we have identified various different imagined publics, which together with various different aims of policy actors are shaping the observed pattern of topics. We have summarized these findings in Figure 1.

Our analysis shows that each group of strategy actors reflects and addresses a particular imagined public and that these publics influence the notion of personalized medicine and thereby potentially also the version of personalized medicine implemented in the Danish healthcare system. In the first time period studied, the imagined public is a research subject or a patient with the main goal of being treated or facilitating future treatment. The person trusts the researcher or the physician. Personalized medicine is envisioned in multiple forms and as influencing the whole healthcare system from research to prevention to diagnostics and treatment. The focus is on creating the optimal conditions for research and development with a wish to investigate all imagined possibilities within personalized medicine, including all citizens in the creation of a national reference genome, prevention and treatment.

In the second time period studied, the imagined public is a patient undergoing treatment. The public consists of patients who trust the public institutions of the
welfare state and also need guidance from public actors in order to navigate the complex field of personalized medicine. At the same time, citizens are also depicted as central actors in the realization of personalized medicine, and thus it becomes critical to signal how public institutions will handle ethical issues. One solution to the handling of ethical issues is to place all activities in public institutions, focusing less on research, and emphasizing public control over all collaborations.

In the third time period studied, the imagined public is a citizen. This citizen trusts public institutions, but may also come to question the trustworthiness of these institutions. The strategy actors see this mistrust as being influenced, among other things, by the behavior of large tech companies. To respond to this, public institutions must convince citizens as to the public institutions’ good intentions and capability of caring responsibly for the collection, storage, and use of genetic data. This orientation towards data security fosters an even more intense focus on ethical issues, especially the citizen’s privacy and the healthcare system’s secondary use of data. To soothe the citizens, policy documents and strategy actors emphasize the importance of establishing a strong relationship between research and patient treatment, and establishing an almost exclusive focus on patient treatment.

Imagined publics can either be explicitly constructed or implicitly implied in policy documents and statements from political actors. Either way, our analysis has shown that an imagined public can frame strategy development and consequently the implementation of personalized medicine. If the background for these changes in strategy focus remain unexamined or unacknowledged, this can pose a democratic problem in that not knowing the rationale behind the argumentation and framing of a problem makes it difficult to engage in a meaningful exchange of views. As we see it, strategies and policies are shaped to respond to the imagined public of specific strategy actor groups. Different strategy actors have varying aims and therefore also envisage different imagined publics. National political strategy actors often associate a concept like personalized medicine with international political currents like e.g. the notion of bioeconomy or the value of

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Figure 1. Connection between strategy actors and imagined publics.
health data, while research strategy actors are more focused on clinical benefit and – effects. It is not so much that specific imagined publics are adjusted to serving specific aims, but more that specific aims turn attention towards specific publics.

Investigating the included documents, we identified that the perception of the imagined publics evolved throughout the strategy period. But analyzing the interview material, it became clear to us that the competing perceptions of the public – as research subject, patient, and citizen – continue to coexist between the different actor groups. The shift in the dominant imagined public in the three time periods is an expression of different actors having the power to establish the most relevant imagined public, at a particular time, in the strategy process. As Rodhouse points out, different imagined publics can be developed at the same time and thus co-exist, apparently representing the same group of people (Rodhouse et al. 2021). What we see in the Danish case is that various different policy actors drive the strategy process, each with a particular perception of the public and a particular aim of personalized medicine. The “imagined public” as concept helps to make visible different framings of complex problems and helps to uncover the argumentative work of policy documents addressing important societal issues. By using this concept, we show a diversified perception of the public: as source for the realization of personalized medicine, as beneficiaries of personalized medicine, as trusting citizens, as worried citizens, and as taxpayers.

The perception of a public in policy papers is not static. As we have shown, the imagined public has an impact on the strategy development and thereby potentially also on the version of personalized medicine implemented, but the imagined public is also formed in response to societal dynamics. As described earlier, the establishment of the National Genome Center induced an intense public debate about the intentions behind collecting, storing, and using genetic data. These discussions made “the citizen” a relevant and active actor in the strategy and policy process. The discussions introduced a new agenda in the argumentation process and the framing of problems. In particular, the national strategy actors were forced to incorporate this need for a new agenda in their argumentation for the implementation and development of personalized medicine, because they were the ones driving the strategy process in the last of the three time periods, and they are also the ones hosting the National Genome Center, as a national agency under the Danish Ministry of Health. From the policy documents and the interviews, we sense that what is at stake here is not only the future of personalized medicine, but the citizens’ trust in public institutions and in their handling of private information in general. The personal identification number in a welfare state and all the national registers connect citizen and state, individually and collectively, in a specific way: the personal identification number produces, on an ongoing basis, a growing archive of information about the interaction between citizen and state (Bauer 2014). Most Danish citizens find it unproblematic that this archived information is used for secondary use (Hoeyer, Bauer, and Pickersgill
probably because people in the Nordic countries tend to perceive the welfare states as participatory and friendly (Bauer 2014). The downside of these information collection practices of the welfare states is the ease with which these practices can be turned into regimes of surveillance (Bauer 2014) or profit-making. Our case shows that work is needed in the welfare state in order to prove the friendly intentions of data collection, and the ways data collection will work for the common good.

Ethical and regulatory issues have been a central part of the political debate about genetics and personalized medicine, reflecting the historically close relationship between genetics and eugenics. Despite efforts to dispel this impression, for example in the Human Genome Project, by focusing on medical treatment, the fear connected to genetic research seems to lurk under the surface at any time (Reardon 2017). As we see in this analysis, the fear of data misuse seems to test the relationship between citizen and state. The solution of the Danish strategy actors in response to the concerns of their imagined publics, is strong public leadership and data control – a solution that would perhaps not be well received in other countries (Reardon 2017).

When looking at the pattern of disappearing and emerging topics and arguments during the three time periods, it seems as if the conditions for developing, implementing, and participating in personalized medicine are downplayed throughout the different strategy documents. Our analysis points out that the more critical the public is imagined to be, the more topics on the importance of public-private partnerships, international collaboration, data security, and investments in research disappear from the documents. We noticed that on the one hand national strategy actors emphasize the importance of transparency, and on the other hand parry concerns by downplaying the role of private actors and emphasizing public control and public institutions. This shows that the imagined public holds the power to shape and direct strategy and policy development and thereby also the power to shape the development of our society. Drawing the attention of the key actors’ different perceptions of the public, is crucial to uncover the positions we, as citizens, are offered in the public development of society.

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**References**


