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Personalized medicine aims at tailoring treatment to the individual person through the sourcing of multiple health data from the population. The realization of these ambitions rest on the ability to reuse health data. But what does it take to reuse tissue and data collected from individuals in connection with treatment, for future purposes? It takes an “enabling public” consisting of not only people providing tissue and data, but also clinicians, researchers, and civil servants. Based on fieldwork and interviews from Denmark, we investigate how use attaches tissue and data to various actors in the enabling public. We argue that multiple forms of attachments and detachments co-exist and that these persist over time. Attentiveness to the character and coexistence of these attachments is crucial in discussions of the role different actors should play in the governance of tissue and data.

**Keywords:** use and reuse of tissue and health data; attachment; detachment; Scandinavia; enabling public

**Introduction**

Personalized medicine holds the ambition of tailoring diagnosis, prevention and treatment to the individual person through the integration of data from the population (Parry and Greenhough 2018; Prainsack 2017). These advancements in medicine are not only expected to benefit the patients, but also to lower healthcare costs and ensure profit (European Commission 2018). Yet, the realization of these ambitions rests on the possibility to reuse health data. How is reuse (for future purposes) of tissue and data collected from individuals in connection with treatment...
made possible? In answering this question, we investigate the complex and multiple attachments and detachments which reuse of health data creates for “the enabling public”. With the concept of the enabling public, we refer to people – patients, clinicians, researchers, civil servants – who, either personally or professionally, are involved in making the use and reuse of data or tissue possible in various ways, thereby becoming affected by it.

Use of tissue and health data has spurred discussions about rights to access and control data. Barbara Prainsack (2019) points out two tendencies in relation to assigning control over data. One tendency ascribes control to the individual from whom the data originated, while the other ascribes control to collectives such as public (healthcare) institutions or governmental bodies representing a population. Individual control typically comes in the form of informed consent from the person the data derived from. As a bioethical concept and practice, informed consent focuses on the autonomy of the individual and does not take into account that several actors can be entitled to tissue and data (Ballantyne 2020; Mittelstadt and Floridi 2016; Parry and Gere 2006). In the context of genomic science, collective control has been discussed as a way to ensure the use of data for the public good (Prainsack and Van Hoyweghen 2020) and expose the need to focus on the rights of marginalized and/or indigenous populations whose samples become included in research databases (Kowal 2013; Reardon 2011; Reardon and TallBear 2012). Although individual and collective control do not mutually exclude each other, we do not know much about how the two forms of control play out in personalized medicine where reuse of data takes center stage. This is what we investigate in this article based on a case-study from Denmark. We show that use of tissue and data facilitates tissue and data’s attachments and detachments to both individuals and collective institutions, and that that these attachments and detachments persist even when tissue and data are used for new purposes. With attachment, we refer to a moral relationship which binds a person to another person or thing (in our case data) (Navne, Svendsen, and Gammeltoft 2018; Pinel and Svendsen 2021). With detachment, we refer to a loosening of the relation. Importantly, detachment does not annul a relationship (Candea 2010) to data, but is a particular way of standing in a relationship to data by way at a distance. Where studies on the data economy have highlighted the relationality of data (Leonelli 2012), the concepts of attachment and detachment help us characterize and deepen our understanding of the relationships data enter in context of use and reuse. We argue that multiple and co-existing attachments (and detachments) to the same tissue and data do not weaken the legitimacy of continuous use, but may strengthen it. This finding suggests that if we are to ensure that reuse of tissue and health data is viewed as legitimate, we need open discussions of the various actors’ role in governing the material.

This study analyses three situations where health data are used (1) in the clinic (2) for research and (3) and in the effort to centralize data storage to enable further reuse. We describe how use in different situations to a large degree is seen as
unproblematic by different actors. Denmark has a long history of holding collective control over data as consent to treatment in public healthcare presumes consent to storage of tissue and data in public registries which then come to constitute a public resource for research (Bauer 2014; Nordfalk and Ekstrøm 2019). As the reuse of tissue and health data has already been integrated into the operations of Danish healthcare services, Denmark and the other Nordic countries are often seen as role models for how to mobilize large amounts of data for research (Tarkkala, Helén, and Snell 2019; Tupasela, Snell, and Tarkkala 2020). Our study helps shed light on why reuse of tissue and health data to a large degree goes uncontested in Denmark but also adds to our understanding of why reuse can be disputed. Given that our informants did not distinguish between tissue, genetic information, and other forms of health data, we use the term tissue and health data to cover samples and health information (including genetic information) generated during their period of contact with the healthcare sector and stored in a biobank or in the electronic health record of the patient and/or in national health registries.

In the following, we describe our analytical approach followed by the setting and material on which we base our analysis. We then describe the three situations where tissue and health data are used. We end by situating our analysis in a Danish public debate on the reuse of blood samples from a screening program, and by arguing for the necessity of open discussions about which actors should be considered when use of tissue and health data are governed.

**Approaching use in an enabling public**

In her book, “What’s the Use?” (2019), Sara Ahmed asserts that how something is used, by whom and for what purpose, is neither predetermined nor intuitive. In investigating the constructive possibilities of use, she shows that use can change the thing being used and use can add value to what is being used. Use also has temporality: things can be constructed to be used for a certain purpose, but use can also come after, in the sense that some uses are secondary. In that way, different kinds of use tell stories about morality, values, discrimination, inequity, rights, and temporality (Ahmed 2019, 8–12, 23–29). In our material, we describe how tissue and data become attached to multiple actors through use. Accordingly, we do not simply describe “a link between source and sample” (Palmer 2009). We show how use creates an affinity between material and actors beyond the sources of the samples. Where other scholars have taken an interest in the moral, legal or pragmatic questions about ownership or rights to use (see also Ballantyne 2020; Holm and Ploug 2017; Ploug 2020; Prainsack 2019; Quigley 2012; Reardon and TallBear 2012), we focus on the implications of use. We explore how use in itself affects “what gets to count as something to be taken account of” (Parry and Gere 2006, 146). In other words, the practice of using tissue and health data is formative for the categorization of the material. Scholars have argued that the
categories in which bodily material is placed affects which use is seen as legitimate (Palmer 2009; Parry and Gere 2006). However, as we see it, the bifurcation between use and categorization is insufficient to describe what shapes the politics and practices around data and tissue. We argue that it is not only true that “What a “thing” is – the nature of a “thing” – or at least what it is determined to be – profoundly affects how that thing may subsequently be used – economically, socially, lawfully and ethically.” (Parry and Gere 2006, 139). The use of a “thing,” which holds many potential meanings, affects what a “thing” is determined to be. We also describe how use of data and tissue sometimes facilitates detachments. Previous studies on the donation of bodily material show the necessity of detaching the material from patients before it can be used for research (Waldby and Mitchell 2006) or made available for other patients (Hoeyer 2016). However, what comes to the fore in our study is the complex character of concurrent detachment and attachment. Use detaches tissue and data from individuals in one context, while allowing for their continued attachment in other contexts.

Whereas others have studied how publics arise in relation to the creation of a specific database (Amelung and Machado 2019), in relation to genetic research (Hinterberger 2012), or through public debate (Martin and Donovan 2015), our interest in the enabling public directs attention to the actors who enable and are affected by the multiple forms of use of tissue and data. In this study we have focused on the patients who deliver tissue and data and rely on their use in the clinical encounter, and the clinicians, researchers and civil servants who use tissue and data and facilitate use through their work. Thus, our concept of the enabling public brings different kinds of people into the same study (patients, health professionals, researchers, civil servants) due to their involvement in facilitating the use and reuse of tissue and data. We do not view this public as a stable entity “out there” for us to study. Rather, we see the public as consisting of unstable groups of people (Horst 2008) which changes as a results of the issue of interest (Marres 2005, 2007) and through the methods we use to study them (Law 2009). Accordingly, the enabling public is not a well-defined group of actors. In the following, we will briefly describe the setting for our study and our empirical material.

Settings and materials
We use the recent state-initiated introduction of personalized medicine in Denmark (Danske Regioner et al. 2015) as an opportunity to describe how use and attachments/detachments unfold when tissue and data are stored by the Danish healthcare sector (see also Gjødsbøl, Winkel, and Bundgaard 2019; Terkildsen et al. 2020). Denmark is a tax-financed welfare state with universal access to healthcare (Mainz, Hess, and Johnsen 2019). It is ranked as having one of the most digitized public sectors in the world (United Nations 2020), including a high level of digitization in the healthcare sector (OECD 2015).
Information generated in the healthcare sector is legally required to be registered in patients’ medical records (Sundheds- og Ældreministeriet 2018a) and in different designated registries (Thygesen et al. 2011). Additionally, Denmark has comprehensive biobanks which store surplus tissue collected in relation to treatment and research. Information from the different registries can be linked through the social identification number assigned to all inhabitants at birth or immigration (Bauer 2014). Research on registry data does not require ethical approval from the National Committee on Health Research Ethics. In some cases, legislation allows researchers exemption from consent for using registry data (Sundheds- og Ældreministeriet 2017) and tissue (Hartlev 2019) for research purposes. Thus, these organizational and legal arrangements ascribe control of data for research purposes to public institutions. In national policies, the comprehensive national registries have been emphasized as a unique resource for the introduction of personalized medicine. In 2016, the Danish government launched its strategy of personalized medicine (Sundheds- og Ældreministeriet 2016, 2021), including the establishment of the Danish National Genome Center. The purpose of the center is to function as a government agency facilitating the use of genetic data in research and clinics, and as a national registry containing genetic information from Danish citizens.

In the founding years of the Danish National Genome Center, several advisory boards were appointed, which were put in place to provide input into the legislation process, advice on ethical aspects, and to comment on specific information material. The advisory boards were only temporary and existed for a period of up to three years. Members of the boards were invited by the Danish National Genome Center and included researchers, policymakers, clinicians, and patient representatives. We observed meetings across four advisory boards from their establishment in early 2018 to the end of 2020. Both authors participated in a meeting with one board, the second author as a member of the advisory board appointed by Danish Universities, and the first author as an observer. In another advisory board, only the second author participated as a member. In a third board, only the first author participated as an observer. In participating as a member of the advisory boards, the second author brought findings from our studies, e.g. about the concerns of citizens and ethical challenges related to interpreting and pooling data, into board discussions. Accordingly, we simultaneously observed the implementation of the national infrastructure while actively participating in its formation by extending the knowledge base for discussions. After the advisory boards were dissolved, we interviewed three officials working at the Danish National Genome Center. The first author also interviewed patients and health professionals from two hospital wards in two cities in Denmark in the period 2018–2020, in one department for hematology and one department for clinical genetics. In the field of hematology, she interviewed five health professionals and five cancer patients. In the field of clinical genetics, she interviewed five health professionals and the parents of seven children with rare diseases.
Accordingly, a total of 25 interviews were conducted. Informants were asked about their opinions regarding who they think should be able to access which health data, for which purposes, under which conditions. Some of the professionals we interviewed were functioning as both researchers and clinicians with responsibility for patients’ treatment. Just like our dual identities as social scientists studying personalized medicine, and professionals participating in advisory boards on the implementation of personalized medicine, the clinicians had dual identities in terms of both caring for patients and conducting research partly based on samples from previous patients.

All interviews were transcribed verbatim. All informants have been given pseudonyms. Drawing on thematic network analysis (Attride-Stirling 2001), our material was coded through an iterative process where we sought to identify what is at stake to different actors in situations where health data are (re)used. This brought to the fore the multiplicity of use and the nexus of attachment and detachment. In Denmark, ethical approval of qualitative studies is not required, but all the involved medical institutions approved of our study, and our data was handled in accordance with the Danish Data Protection Agency.

The fields of hematology and clinical genetics are both seen as central to the introduction of personalized medicine in Denmark (Danish National Genome Center 2021). At both departments, genetics play a role in diagnostic processes, yet in different ways. In hematology, genetic tests are run to look for variations in specific genes, or tumor tissue is sequenced to understand the genetics of the tumor. Here, patients are not always aware that a genetic test has been undertaken since the information only concerns specific genes or the genetic make-up of the tumor, and the genetic test does not require any additional consent. In clinical genetics, a genetic test aims to map disease-related hereditary traits which may affect both the individual patient and their relatives. The test may reveal secondary findings which represent genetic variations which do not relate directly to the disease under inspection and might be of unknown significance. Because of the hereditary aspect and the risk of secondary findings, the patient is informed about the implications of taking a genetic test and is obliged to sign a separate consent form. As many patients in clinical genetics are children with rare diseases, their parents need to consent to the children’s genetic testing. While this situation raises ethical questions about whether parents should be able to consent to the return of secondary findings on behalf of children (Ó Cathaoir and Hartley 2019; Ormond and Cho 2014), these questions did not appear as points of discussion in our interviews with parents and clinicians. Yet, talking to cancer patients and parents of children with rare diseases undergoing genetic testing faced us with the analytical and ethical challenge of introducing questions about reuse of to be people in vulnerable situations who might be unaware how data can be reused (see also Sheikh, Deleuran, and Hoeyer 2016). Here, situational ethics (Castañeda 2006) helped us respond to needs of the informants which sometimes meant that the interview took a different direction than what was originally planned. Below, we draw on
these challenges to understand clinical situations where reuse is given little attention.

We now turn to the analysis of how tissue and health data are used in different situations. We begin in the clinic.

**Use of tissue and data in the clinic**

Tissue and data used in contact with the healthcare sector is first and foremost generated with the purpose of informing medical decision-making and is, in many cases, a prerequisite for receiving preventative measures and treatment. Using Ahmed’s terminology, we can say that tissue and data are generated for the purpose of informing medical decision-making (Ahmed 2019) which can help individuals and families. When used in the clinic, tissue and data are tethered to the individual by health professionals in the sense that tissue and data are seen as representing the individual’s health. The conviction that tissue and data represent individuals was shared by the parents of children with rare diseases with whom the first author talked. One example is Trine and Jens; parents of Sarah, who was 17 when the first author interviewed them. Her parents explained how Sarah “is completely dependent on our [the parents] help all the time, 24 hours a day.” After many years of frequent contact with the healthcare sector the family were offered a whole genome sequencing. The whole genome sequence detected a variation that could explain Sarah’s condition, but which did not have any treatment potential at that point in time. Despite the condition lacking treatment potential, Trine and Jens said that they experienced a sense of relief upon receiving the results. This was not because naming the disease changed their relationship to Sarah; they love her just the same as before – but because they received an explanation for Sarah’s struggles. Other families also pointed out that gaining knowledge about their child’s condition enabled them to offer their child support in a more purposive way. Consequently, because they viewed genetic information as a representation of their child, the results often affected how they understood and responded to their child, even if the result did not have any clinical implication.

For Trine and Jens, the knowledge generated from the genetic test was also somewhat painful. When the first author asked them how it felt to receive the information that Sarah had an uncommon genetic variation, the conversation became somewhat uncomfortable, and the first author could sense this was a painful topic for them. After a short period of silence, Jens said: “The reason why Trine is a bit hesitant here is because they found out that I have a genetic variation, which is a very small part of my cells which I 100% passed on to Sarah.” Later in the interview, Jens returned to how he experienced receiving the information that he was a carrier of the genetic variation causing Sarah’s disease. He said that it had caused him great emotional distress and that he had felt alone with these feelings. He wished that the healthcare sector had offered him some form
of psychological support afterwards. Jens, without knowing it, had been a carrier of the genetic variation and thus felt guilty for Sarah’s condition. Experiences of guilt in relation to the provision of genetic information is a topic previously described in literature on social aspects of genetics (Konrad 2005; Sachs 1998). To Trine and Jens, the information which explained Sarah’s condition did not result in any treatment. Nonetheless, because they viewed tissue and data as representations of themselves and their daughter, the information changed Jens’ self-perception and the parents’ understanding of their daughter.

In the case described above, tissue and health data are used to help individuals. In this situation, tissue and data are seen as representations of individuals which make all actors enact a strong connection between sample and source. In Denmark, there is no routinized practice of taking some extra tissue, but in case there is extra tissue from e.g. a biopsy, this tissue is stored by public healthcare institutions and continues to be available for clinical use. Thus by adhering to the law that consent to treatment presumes consent to storing of tissue and data, the enabling public of clinicians and patients facilitate (re)use of tissue and data by moving tissue and data into storage. With this arrangement, tissue and health data enter a “data assemblage” (Kitchin and Lauriault 2018, 3) which enables tissue and data to be used for secondary purposes unrelated to the initial clinical context; purposes that we – according to Ahmed’s terminology – can describe as use after (Ahmed 2019). This leaves tissue and data with the potential of holding concurrent attachments to both the individual and to the healthcare institution. However, in clinical encounters the potential for using tissue and health data for secondary purposes was given little attention, as we will turn to now.

**Consent for storage and reuse**

In Denmark, the routine storage of tissue and data from clinical consultations is in most cases not mentioned in health professionals’ interaction with patients. In this way, the relationship of trust between patient and health professional in the clinical use context becomes the basis for using tissue and data for secondary purposes. However, in some cases, for instance when tissue for local biobanks or data for certain registries are collected during treatment, patients are required to give consent for the storage of samples and their potential reuse (Ó Cathaoir 2019). This was the case at the department of clinical genetics, where individuals who were tested for a specific genetic variant were asked to give consent for the storage of data in “relevant registries.” Inge, a genetic counsellor, described to the first author how she told individuals that the department stores DNA with the purpose of using it for future diagnosis “if your children or your grandchildren ever want to take up such a case.” While the consent form states that the registries aim to aid clinical work and generate data for research, in facing patients Inge emphasizes the possibility of using data for clinical work. Our impression was that this was not to conceal anything from patients, but that in her interaction
with patients, the potential reuse for research seems less relevant. In the clinical context, she categorizes tissue and data as information about individuals and does not give its potential as research material much attention. Similarly, the parents of children with rare diseases and the cancer patients the first author talked to did not think about use for research in the situation where tissue and data were used in the clinic. Sine and Magnus, parents of Storm, who was about one year old at the time of the interview, had all had their genome sequenced when Storm was urgently admitted to hospital after experiencing hemiplegia. The test showed that Storm carries a rare genetic variation which causes neurological defects if left untreated. When the first author asked Sine and Magnus about their thoughts on the potential reuse of their samples for research purposes, they seemed surprised about this possibility. It was not something they had thought about. Magnus said:

We did the test to find out about his disease (...) To find out where it [the symptoms] was coming from or what made him sick. I don’t think it even crossed my mind that it could be used for something else.

It may come as no surprise that the potential reuse of data or samples seems irrelevant in a situation where a child is partly paralyzed, and parents and doctors desperately want to find out the reason why. In many of the conversations the first author had with parents of children with rare diseases and with cancer patients – including those who had a less acute course of events than Storm – the first author felt uncomfortable asking about their thoughts on reuse. They had so many other things at stake which could possibly affect their future that questions about reuse seemed inappropriate and felt intrusive. In reflecting on the first author’s experiences, we realized that not only were tissue and data attached to the individual, but also that attachment has moral implications. In the interview situations, questions about reuse diverged from what the first author perceived to be most important to the parents and cancer patients: the individual’s biography and the way tissue and data related to this. Questions about reuse potentially detached tissue and data from the individual and their life, disease, and suffering, and caused the first author moral discomfort. It was not that parents or cancer patients were against the possible reuse for research when they were confronted with the potential of tissue and data being used for research, on the contrary, many actually viewed it as positive. Nevertheless, to introduce patients to data being categorized as something other than information about individuals seemed inappropriate to the first author. This experience may help us understand why Inge from the clinical genetics department gives limited attention to the potential future reuse of data and tissue for research and instead focuses on how storage of DNA may help patients and their families in the future. The health professionals might, like the first author, feel unconformable introducing the possibility of using data for secondary purposes, because it seems irrelevant to suggest the possibility of unmooring data from individuals in the very situation of facing patients and
using data to help them in their current lives. This discomfort raises questions about how the tension between the two use situations – the treatment situation in the present and the research situation in the future – can be resolved. As we shall discuss at the end of this article, when data and tissue in biobanks and registries are designed to be used for future research, the enabling publics’ attachment to tissue and data is crucial to account for.

Though the parents did not give reuse much thought in the clinical encounter, they were not surprised to learn that the hospital stored samples from previous clinical encounters. More parents told the first author that they had initially been reluctant to accept a whole genome sequencing because they feared it would imply taking a blood sample from their child. They were relieved, but not surprised, to learn that the test could be undertaken by using stored blood samples from previous consultations. This indicates that patient and clinicians see the accessibility of the welfare state to tissue and data as a self-evident platform for their interaction and that this use enables all the use that come after. To sum up, in the clinic when tissue and data are used to help patients, they are attached to individuals and come to belong in the category of personal information. Here, patients and families who are focused on finding a diagnosis and treatment are at the same time trusting the ethical procedures of health authorities. In this situation, they do not experience the tissue and data’s attachment to welfare state institutions as contradictory to tissue and data’s attachment to them as persons, but as supporting tissue and data’s attachment to their biographical lives. Consequently, in this context, the facilitation of reuse comes into being by the enabling public (represented by parents of children with rare diseases, cancer patients, and clinicians) only giving very limited attention to reuse beyond the clinic. Conversely, as we will turn to next, the patient from whom tissue and data originates is given limited attention when it is used for research.

Repurposing of tissue and data: detachments from the patient and new attachments

In interviews with researching clinicians, we found that when tissue and data are reused for research, the material is no longer categorized as information about that person (see also Quigley 2012; Waldby and Mitchell 2006). The researching clinicians see tissue and data as detached from the individual it originates from. In an interview with Mie, a doctor at the hematology ward who carries out research, Mie said she thinks tissue and data ought to be used for research:

If the purpose is to gain more knowledge to be able to help people who have a specific disease, then I think that purpose should be given most weight. At least in the cases where we have taken samples from the freezer, there has not been any risk of harming the individual patient or [any risk of the sample] being traced back to the person. The [research] interest has simply been on a cellular level to see what happens in the single cell.
In conducting research on tissue, Mie no longer sees the patient in the sample. It is now simply a blood sample—a collection of cells. She justifies her interest in tissue and data by categorizing it as research material which does not contain personal information. We encountered a similar attitude among parents to children with rare diseases and among cancer patients who said that they see use for research as positive, provided that tissue and data remain anonymised. We interpret this request for anonymisation as a way of stating that the legitimacy of research depends on information being categorized as something other than information about people. Thus, anonymisation becomes a way of detaching tissue and data from patients.

As described above, the registration of health data in medical records and the storage of tissue in biobanks in relation to their clinical use context form the basis of reuse. This banking and registration facilitates the use that comes after by creating the potential for tissue and data to become something other than representations of individuals (Nordfalk, Olejaz, and Hoeyer 2022; Svendsen and Navne 2022). This became clear to us when researching clinicians let us know that the unmooring of tissue and data from patients did not imply that tissue and data can be used by anybody. Like most clinicians the first author talked to, Mie’s immediate response when asked about her opinion on the possibility of using health data for research, was “Well, there are very clear rules regarding that.” The researching clinicians see reuse as something being regulated by the welfare state, and their instant reaction to questioning about their own opinion is to explain the existing rules. In these conversations, the clinicians see registration and banking as acts which attach tissue and data to the welfare state by allowing the state to act as the custodian of tissue and data. Mie and the other researching clinicians know the regulatory system that grants access and are familiar with what they describe as the sometimes tiresome process of requesting access. From their perspective, the regulatory system embedded in the welfare state is to decide what defines proper use. The detachment from patients accordingly elucidated the attachment of tissue and data to the welfare state. In the research context, this attachment was essential for reuse to be legitimate.

Vibeke is a molecular biologist who carries out genetic research at the department of hematology and does not have patient contact. In an interview, she said that the attachment to the welfare state is necessary if tissue and data are to realize their full research potential, meaning that data would be available to use for research and not only in clinical encounters. In referring to the regulatory system, she highlighted the possibility of seeking exemption from renewed consent from patients:

When you have such a unique biobank as we have here, where we have leftover material enabling you to get a patient group of a sufficient size, then I also think that it ought to be taken advantage of. I think it would be such a pity to not be able to touch it because you cannot seek exemption from informed consent.
Vibeke contemplates over the importance of constructing large enough populations to be able to make substantial research. In this way, she too categorizes tissue and data as something giving insight into a cohort, rather than individuals, and argues that use for research becomes a way of adding value to tissue and data (Pinel and Svendsen 2021). What we learned from the interviews is that, for this potential to be realized, data needs to be detached from patients and not represent them as individuals, yet be firmly attached to a regulatory system deciding what it can be used for, who can gain access to it, for how long, and under what conditions (e.g. exception from consent). Thus, the enabling public of researchers facilitates reuse by attaching tissue and data to welfare state registries and institutions, making tissue and data perpetually bioavailable (Cohen 2007; Bharadwaj 2008) in the understanding of becoming ready to enter scientific practices. To the researchers, this intertwined detachment from individuals and attachment to welfare state was successfully completed when the samples appeared as cells or patient populations rather than as a description of individuals. The detachment of tissue and data also implies that in this situation patients are not seen as entitled to have a say in how it ought to be used. However, this does not mean that researchers would see tissue and data as permanently cut off from patients. In the interview, Vibeke repeatedly mentioned that in the clinical context, patients had initially given their consent for data and tissue to be stored. Accordingly, Vibeke is very aware that the samples derive from patients, and she reflects upon the conditions under which samples were collected. Consequently, detachment between patient and data is not an erasure of a relationship, but a particular way for the patient to stand in a relationship to data: being at a distance, but still holding a connection. To Vibeke, it was the job of the welfare state – and not the patients at a distance – to regulate reuse in a way which was acceptable while allowing data to reach its full research potential (Pinel and Svendsen 2021). This illustrates the co-existing attachments and detachments which enable reuse of tissue and data. Vibeke attaches tissue and data to patients and categorizes it as information about patients due to the original clinical context in which patients gave consent. Yet she also sees the very same material as detached from patients and as a population which is used for research (Nordfalk, Olejaz, and Hoeyer 2022). This simultaneous attachment and detachment is enabled by the welfare state, which is able to regulate the multiple uses in a way that makes Vibeke perceive reuse as desirable. Accordingly, data’s mutual attachments (to patients, to welfare state legislation, to the domain of research) enable rather than exclude each other.

Centralising data storage while respecting attachments

The establishment of the Danish National Genome Center aimed at centralizing the storage of genetic information. This central storage would enable pooling of genetic information to make more robust cohorts and create easy access to the information for researchers. This aim implied that local cohorts of genetic data,
collected by researchers like Mie and Vibeke, could be accessible for other researchers. Accordingly, our third case describes discussions about how best to build an infrastructure enabling further reuse of tissue and data. Through these discussions, multiple actors’ concurrent attachments to the same material became clear to us.

Though it was difficult to distinguish between statements from our informants about genetic data and statements about other kinds of health data, this distinction exists legally. Since 2004, it has been possible for patients in Denmark to opt out of tissue samples being used for anything but their direct treatment. In 2019, after a comprehensive public debate about the Danish National Genome Center, new legislation stated that patients should also have the possibility of opting out of their genomic data collected during treatment being used for research (Sundheds-og Ældreministeriet 2019a, 2019b). Consequently, this legislation treats tissue samples and genetic data as being more sensitive than nongenetic health data. Accordingly, patients whose genetic data would be stored centrally in the Danish National Genome Center would need to be informed about their opportunity to opt out of their data being used for research (Sundheds- og Ældreministeriet 2018b). At the Danish National Genome Center, the advisory boards were asked to discuss how this information should be provided to patients. The members of the advisory boards generally welcomed the proposal that patients be informed about the possibility of opting out. Nevertheless, it was noted by members of the advisory boards that opting out should not be “too easy.” The members feared that if opting out was too easy and too many took this option, it would jeopardize the opportunity to carry out research on a representative part of the population (see also Nordfalk and Hoeyer 2018). In these discussions, as with the quotes from Mie and Vibeke, the emphasis is on how to ensure that tissue and health data reach their full research potential. As we experienced these discussions, the comments about “opting out not being too easy” expressed the view that, from the perspective of board members, tissue and data were already seen as being detached from patients. Nevertheless, data’s attachment to patients which had arisen through previous use was not disregarded which serves to show the continued connection between “source and sample” (Palmer 2009, 25).

Discussions within the advisory boards in the National Genome Centre also illustrated the attention given to who uses tissue and health data. In one board, members discussed how the return of genetic information from research projects to the National Genome Centre should be carried out. In this discussion, several board members, who were also researchers and researching clinicians, expressed concerns that they would lose the right of disposal over tissue and data they had generated during laborious research projects if genetic information were to be stored centrally. During a research project, when exactly should a transfer to the National Genome Centre take place? When should other researchers be able to access what the original researchers viewed as their tissue and data? These concerns about the researchers’ access to data emphasized attachment between
research data and researchers. Where interviews foregrounded attachments of data to patients and to public healthcare institutions (as we have discussed in previous sections), the discussions in the National Genome Centre brought to the fore the attachment of data to researchers.\(^1\)

The worries regarding tissue and data that existed among researchers were reiterated in interviews with employees at the National Genome Centre, who told us that in building a centralized database they were highly aware of not taking genetic information out of the hands of the researching clinicians who had generated it. In one interview, Henrik, an official working at the National Genome Centre, told us: “You sense that there are researchers on the board who are very attentive to how their data continues to remain their data when this data is reported to the National Genome Centre.” Here, an attachment between researchers and tissue and data has arisen, not because the researchers have changed the material through their labor (see for instance Parry and Gere 2006), but because a tie between researcher and the material has arisen through its use. The civil servants we interviewed also saw it as their task to ensure that this attachment to the corresponding researchers was respected. Their statements expressed the view that researchers build relations to the data they produce (Pinel, Prainsack, and McKeivitt 2020) and that these relations should be respected even when this might impede data sharing (Vezyridis and Timmons 2021). At present, there are still outstanding decisions to be made regarding how to regulate the return of data from research to the national database. The instructional directive from the National Genome Center currently states that genetic information has to be reported at the end of a research project or “occasionally” [ved lejlighed] (Danish National Genome Center 2019, 10). This language illustrates that no formal decision on how to detach tissue and data from clinical researchers has yet been made, thus there is still no solution to this issue. The conversations in the Danish National Genome Center and the interviews about the implementation of new legislation show that the enabling public of board members and civil servants facilitate reuse by balancing the concurrent attachments between data and patients (patients need to be informed about their opt out opportunity as data is tied to them), between data and welfare state institutions (research data has to be returned and “attached” to the Danish National Genome Center), and between data and researchers (researchers’ attachment to data they themselves have generated should be respected). Thus, it is not only patients who are attached to tissue and data through its use; researchers also become attached to the material through previous use in a way which gives them a right to access and control the use of data.

**Continuous attachments**

When tissue and data collected in contact with the healthcare sector are stored in biobanks or in registries, these items become part of a data assemblage facilitating
various uses and multiple attachments among people in the enabling public. In the clinic, tissue and data are used to inform medical decisions. In this context of use, health professionals and patients attach tissue and health data to people and view these items as representing people. Here, it is challenging to engage in conversations about the use of tissue and data for purposes outside of clinical use because it takes focus away from what is important in the clinical situation: how tissue and data can help the individual. When tissue and health data are reused for research, they are utilized in a way which makes researchers see tissue and data as detached from patients: they are not categorized as information representing the patient in that use context. This separation between patient and data is important for facilitating reuse, but for both researchers and patients it is equally important that tissue and data are attached to the welfare state, which they see as entitled to decide on proper and improper use. Finally, members of advisory boards and civil servants in the Danish National Genome Center attach data to researchers. What does this unearthing of data and tissue’s attachment to different actors make us see? It shows us that reuse is not simply a question of a signature on a consent form. Rather, (re)use of tissue and health data is an achievement which depends on patients’ trust in healthcare authorities, the creation of tissue and data reserves as a task of the welfare state, and the negotiation of researchers’ continuous access to data in storage. Moreover, we show that reuse becomes possible by the enabling public of patients, clinicians, researchers, civil servants crafting various actors’ attachments and detachments to data. Surprisingly, maybe, our case uncovers that overlapping attachments and detachments actually make reuse uncontested.

Does this imply that Denmark has found a way to ensure that the reuse of tissue and health data for research purposes is always viewed as legitimate? This is not the case. Public controversies and critical media coverage show that reuse of tissue and data can be contested. One example can be found in a Danish newspaper article from 2018 (Stryhn Kjeldtoft 2018). In the article, we learn that a research project named “iPsych” uses anonymized samples from neonatal dried blood spots collected as part of a screening program to explore the relationship between genetics and psychiatric disease (Pedersen et al. 2018). The article featured an interview with the 18-year-old Lise whose neonatal sample is likely to be used for research in iPsych as Lise has previously suffered from severe depression. At her birth, her parents gave their consent for the potential reuse of data for research when the sample was taken; however Lise was not asked for her consent directly and feels “completely naked in front of a distant audience, except it is what is inside me that they are looking at” (authors’ translation) (Stryhn Kjeldtoft 2018). To her, it is not only the samples that are used, but also her as a person. The attachment constituted through the original use – related to disclosing possible disease risks at her time of birth – persists 18 years later even though her parents gave their consent for the data to be reused. Lise’s views on the possible use of a blood sample from her body elucidates that tissue and data can be attached to
several actors simultaneously, and that the detachment of data from patients is not necessarily finite. If the researchers from “iPsych” hold views similar to Mie and Vibeke, they too are convinced that they do not see Lise during their research. They see only samples, cells, and data. Conversely, Lise feels that they are looking inside her when they use the samples. Interestingly, Lise states that she would probably have consented had she been asked; it is the fact that her attachments to tissue and data have not been respected which makes her frustrated.

For several decades, the attachment of tissue and data to individuals has spurred discussions about informed consent. Informed consent is used as a measure to enable individuals to transfer the rights to use the tissue from them and data about them to others (Waldby and Mitchell 2006). However, informed consent installs stability (Hoeyer and Hogle 2014) as it implies that patients transfer the rights of use – and thus detach themselves from data – in a finite way. Besides, by foregrounding individual autonomy and control, informed consent does not address that several actors can be entitled to tissue and data as we have found to be the case. In this Danish case, the attachment to the welfare state institutions and to researchers is not necessarily something that is happening at the expense of the attachment of tissue and data to the individual. Accordingly, to account for the complex ways in which individual and collective control intersect, we need open discussions as to which roles the enabling public – not only patients – should play in the governance of the material. Such discussions hold potential to address possible diverging understandings of legitimate access to and use of tissue and data.

The attachment of data to various actors constituted through previous data use is especially relevant when policies aim to make data broadly available. Examples of this are open access policies such as the FAIR initiative, which aims to make research data reusable (Wilkinson et al. 2016) and the Danish initiative “One Entrance to Health Data” [Én indgang til sundhedsdata], which aims to create one webpage facilitating easier and increased use of Danish health data, including commercial companies outside of Denmark (Regeringen 2021; Sundhedsministeriet and Danske Regioner 2021). These initiatives do not address engagement with the enabling public; they solely focus on how to facilitate the reuse of data. Measures acknowledging and considering the opinions of attached actors disappear from the policy papers aiming to execute ambitions of increased use of health data. Accordingly, the actors who have become attached to data through previous use are silenced. Based on our findings, we suggest that this negligence of attached actors challenges the legitimacy of the governance of tissue and health data and might lead to contestations.

Finally, the enabling public of our study consists of people who are all involved in very specific forms of use of tissue and data: patients who are ill with cancer; parents of children with rare diseases; clinicians trying to help patients; researchers trying to gain new knowledge about health and disease based on tissue and data; and civil servants trying to facilitate the sourcing of
tissue and health data. Dixon-Woods and colleagues point out that the parents and children belonging to the “childhood cancer community” constitute a public which is generally more positive towards the use of spare tissue than the public that is normally portrayed in the media (Dixon-Woods et al. 2008). Similarly, the experiences of the enabling public described in this study differ from that of other publics. It is important to understand the experiences with sourcing of tissue and health data in the enabling public, both because samples from patients are used for research more often (Nordfalk and Ekstrøm 2019) and because they provide us with insights into the experiences from which this public forms its opinions. Other publics, or other parts of the enabling public, who experience use of tissue and data from a more distant position, might view attachments differently. To understand what it takes for the use of tissue and health data to be viewed as legitimate, political actors need to take seriously and engage with the enabling publics.

**Note**

1. The law solely warrants the researchers to return genetic material generated as part of a research project, where patients are informed about the return of data to the Danish National Genome Center. However, because the distinction between genetic data and other health data was added to the Danish legislation only in 2018 (Sundheds- og Ældreministeriet 2018b) it was unclear whether members of the board were referring to tissue and health data as narrowly as the legislation.

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**Ethical approval**

The study on which the research is based has been subject to appropriate ethical review according to the Danish rules. According to Danish regulation participants were informed about the purpose of the study and gave their consent to participate verbally. The study has been reported to the Danish Data Protection Agency.
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