

# The Mutual Enablement of Research Data and Care: How Newborn Babies Become a National Research Population

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## Abstract

Public health research depends on access to population data. This article is a study of the practices and the work enabling data collection for public health research. In Denmark, a blood sample is taken from practically every single newborn baby through a national screening programme. These samples can be combined with other health data and used for research purposes without explicit consent from those giving the samples. With an ethnographic approach, I study the practices, the work and the workers of the Danish NDBS samples, and explore how newborn babies come to serve as an important national research resource. From these studies, I argue that the making of national research resources in this way is 'mutual enablement' of research data and care. The work of both health professionals and researchers mutually enables professional care and opportunities for collection of samples and data for research. It is through this mutual enablement of research data and care that newborn babies become a national research population.

**Keywords:** data, care, research population, public health, newborn dried blood spots

## Introduction

Public health research depends on access to population data. This article examines the practices and the work enabling data creation for population research. It asks, "How do babies become data?" and explicitly in this case, "How does a national population become a research population for genetic research?" Using the case of Danish 'newborn dried blood spots' (NDBS) samples, I explore how these samples come to serve as national research data. In many ways, the collec-

tion of Danish NDBS samples represents something of a 'data heaven' for researchers, adding a biological component to the general idea of Denmark as "an epidemiologist's dream" (Frank, 2000, 2003). Moreover, studying the NDBS samples serves as the continuation of the social science work by other STS-inspired scholars. This work has focused on the labour and management of the NDBS samples as a political commodity (Lindee, 1982) and on how the consequences of newborn



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screening can have a major impact on the life of the child and parents (Timmermans and Buchbinder, 2013). Timmermans and Buchbinder (2013) end their inspirational book with five “omens” on the future of newborn screening, the fifth focusing on the retention and future use of NDBS samples for research. This fifth omen is where I initiate my studies. The object of this article is to elucidate practices in how a population of newborn babies in a socially embedded, and often emotionally tense, care situation, becomes research-friendly data.

The Danish NDBS samples serve as a unique case study in this context because of their national collection process. These samples have been taken from almost all children born in Denmark since 1982 (Nørgaard-Pedersen and Hougaard, 2007). Consequently, the samples are considered nationally representative. The samples are a part of the Danish newborn screening programme and therefore has a primary clinical purpose of screening. Through cryopreservation, it is possible to store the samples and later re-use them for research purposes. Using NDBS samples has caused controversy internationally (Couzin-Frankel, 2009), for instance more than 5 million NDBS samples have been incinerated due to lack of parental knowledge and consent for research in court cases across several US states (Waldo, 2009; Lewis, 2015). In Denmark, there are legal exemptions in place to facilitate not only use of these samples for research, but also to link the Danish NDBS samples with register-based data on health, education, employment, and various other data throughout the lifetime of each individual. The Danish legislation allows for the NDBS to be re-used for research purposes without explicit consent from either the child that gave the sample or from their parents, regardless of how old the sample is (Folketinget, 2020). Consent for the sample being stored and possibly used for research purposes is embedded in consenting for the sample to be taken. In a recent research project, for example, more than 80,000 samples were aggregated and genetically sequenced in order to carry out research on the genetics of psychiatric disorders in children and adolescents (Pedersen et al., 2017). Studies like these are only possible if population data are available for research.

In the studies of this article, I focus on the practices that enable newborn babies to become a national research population. Here I am particularly inspired by the term ‘populationisation’ introduced by Holmberg, Bishof and Bauer (2012), as “a process that encompasses the enrolment of the individual into a segment of a population through the compilation and transformation of individual data into population data” (Holmberg et al., 2012: 401). I therefore study the work and the practices when an individual newborn baby has an NDBS sample taken at the hospitals and when these samples are compiled into a population at the Danish Neonatal Screening Biobank.

From these studies, this article argues that the creation of research populations is a case of what I call *mutual enablement* between research data and care.

## Enablement, data and care

In this section, I will briefly introduce the three main terms that shape this article: enablement, data and care.

As to the first term, ‘enablement’, I use this term as a part of my argument of ‘mutual enablement’. According to the Cambridge English Dictionary, ‘enablement’ is “the process of making someone able to do something, or making something possible” (Cambridge, 2020). This definition allows for the consideration of mutualism involved in how samples are enabled as an object in the practices, as well as the study of what the samples enable for the actors involved. In earlier studies, the term ‘enablement’ has been used as the central theoretical concept in disability studies (see e.g. Rapp and Ginsburg, 2001; Whyte, 2014). In these studies, enablement was viewed as a (measurable) bodily function of a human being, or as a focus on patient enablement through the process of treatment (Howie et al., 1998; Mead et al., 2002; Desborough et al., 2017). Enablement has also been used in Science and Technology Studies (STS) literature to describe how ‘enabling arrangements’ can explore independence as a socio-materially distributed, negotiated and continuous accomplishment in older people (Bødker et al., 2019) and how patient engagement with technology can enable the production of measure-

ments (Langstrup et al., 2013). Still, 'enablement' as theoretical concept is not as recognised in STS scholarship as the term 'enactment', which focuses on how an object is performed or implemented through different activities (Mol, 2002). A recent study has proposed that 'enablement' and 'enactment' are in fact intertwined (Carusi et al., 2018). However, as 'enactment' focuses on the object, it has a tendency to leave the actor vague (Mol, 2002). I will argue that the health professionals handling the Danish NDBS samples are not vague, but that they actively use the space to enable possibilities for themselves, and in a larger perspective they, in turn, enable population research. Not only are the data enabled through their hands, but the health professionals mutually enable different possibilities of care through the same process.

As to the second term, 'data', the recurring question discussed internationally by researchers and policymakers is often, 'What are data?' (see for instance Edwards et al., 2011; Kitchin, 2014; Maurer, 2015). In this era of 'big data', when the desire for more data of better quality and on more people permeates health systems (Hoeyer, 2016), social science research has focused on understanding data – how they are identified, produced, circulated and with what implications. Data transform our social relations as well as our working conditions. However, this focus on better understanding existing data leaves a research gap of how these data become data in the first place. This article fills this gap in research with an empirical study of the practices and the actors who enable NDBS samples from newborn babies to become research data. Previous studies on the production of data have found that data do not just exist but are structured through processes of transformations (Denis and Goëta, 2017). Etymologically, the term 'raw data' is a contradiction in itself, as introduced by Bowker (2006) and elaborated by several scholars in "Raw data" is an Oxymoron with an argument that data do not simply exist as a resource, but are the outcome of a process of work: collecting, entering, sorting. It is not 'raw' (like a vegetable from the ground), rather it is 'cooked' (like ratatouille) (Bowker, 2006; Gitelman, 2013; Biruk, 2018). These notions have been crucial for my understanding of the creation

and the existence of data. Here, I extend this work by describing the data work that goes into making a population of NDBS samples into a population of research data. Data work encompasses the sociotechnical practices of producing and using data (Møller et al., 2020) and refers to "any activity related to creating, collecting, managing, curating, analyzing, interpreting and communicating data" (Bossen et al., 2019: 466). Moreover, data work attends to the question of who creates data – i.e. the data workers. Data workers seldom work alone. Rather, they are a part of a larger network together with other data workers. Together, they form an infrastructure for data (Møller et al., 2020). In this article I therefore study both the data work and the data workers: who does what kind of work, and what kind of work goes into each of the practices when the blood from a newborn baby's heel becomes available as data for new research. In contrast to other studies focusing on one kind of work or one kind of worker in data making (see for instance Pine and Bossen, 2020), by studying several practices and actors, my goal is to balance the different perspectives throughout an infrastructure of practices as one larger study. Social and cognitive distance often separates those who create data and those who make use of them (Espeland and Stevens, 2008). As a result, those who use data tend to take the existing data for granted and have little interest in their origin, overlooking the meticulous work of collecting, storing and preparing data. Finally, this article therefore attempts to elucidate the perspectives and experiences of both data creators and data users.

As to the third term, *care*, it is essential to the study of the Danish NDBS samples. I recognise that the definition of what and when something is 'care' can be slippery, and any attempt to actually define 'care' risks becoming insufficient (Martin et al., 2015). 'Care' is a word filled with dependencies. How one defines 'care' is dependent on the context and perspective, and the term 'care' is often used in both scholarly articles and in everyday interactions. When expressing care for someone or something, it often implies an interest or concern (Merriam-Webster, 2021). In the context of newborn babies, care is often associated with motherly or parental care. However,

in this case of the Danish NDBS samples, I argue that the care produced by data might not be the care expected. As this article will show, the actors – such as midwives, postnatal nurses, biomedical laboratory technicians and researchers – who engage with the NDBS samples, express and enable care in multiple ways and directions. These are examples of care in practice. Care in this case is multiple and selective, and a study of what constitutes good care from the perspective of the actors involved is very much dependent on their professional attention and expertise (Mol et al., 2010; Davies and Horst, 2015). They care for institutional goals as well as individual babies. Moreover, this practice is something that is done actively (Mol et al., 2010). Unlike a concern, it is not something they have. It is something they do. They care.

## **Studying the Danish newborn dried blood spots samples**

This article is based on qualitative methods and was conducted as inductive ethnographical research (see e.g. O'Reilly, 2012 on ethnographic methods). Thereby, even though I set out with an initial focus, my analytical perspective was shaped and reshaped by the observations I made and the relations I formed.

### ***Studying practices and work(ers)***

As mentioned, the Danish NDBS samples are taken from almost all children born in Denmark within 48–72 hours after birth. This article builds on fieldwork carried out in two hospitals in Denmark in the spring of 2017. Access to fieldwork in healthcare often relies on gatekeepers (O'Reilly, 2012). Through a collegial connection to a midwife involved in research, I was able to approach two senior managers at a Danish hospital with one of the largest maternity wards in the nation. Following an initial meeting with one of the managers (a senior midwife who was also a principal at the Midwives and Postpartum department), I was given access to all areas of the NDBS sample collection process. At this department, my observations stretched over four days. I visited two different maternity wards and spend one of the days following a midwife on home visits. Subsequent to the observations at the first hospital, I was able

to gain access to another hospital with a smaller maternity ward, as a comparator for my initial observations. Here, the fact that I had gained access at the first and larger hospital, was enough for them to also grant me access to their hospital, and I spent two consecutive days observing NDBS sample collection processes at the second hospital. In total, I carried out 25 observations of NDBS samples being taken from newborn babies.

During my fieldwork, I sought to understand who does what kind of work and where with the Danish NDBS samples. Here, I became aware that the sampling happened in various spaces and was conducted by various health professionals. I first observed samples being taken by midwives and maternity nurses at a maternity ward. Later in my fieldwork, when carrying out observations at the hospital ward where mothers were hospitalised due to complications in their pregnancies or at birth, I found that biomedical laboratory technicians were in charge of taking the sample on their daily rounds. These samples were taken either in the rooms where the mother had been admitted or in a shared room for nursing babies and sample-taking. Some parents were fortunate enough not to have to go back to the hospital, but instead have the midwife come to visit them in their homes. When conducting participant observations during my fieldwork, I would introduce myself and briefly explain my research aim, and ask the parents if they would mind my observing. All of the parents I encountered were willing to be a part of my project. After the sample had been taken, and the parents had left the room, I would write down notes on my observations and conversations. In cases where I visited the family's home, I would write my notes in the taxi between one home and the next. In general, I felt very welcomed during my fieldwork. Reflecting on my own role, I believe it has to do with being 'at home' (Madden, 2010, 45–46) in my field. I experienced a 'familiarity' with the mothers and to some extent also with the health professionals. This is probably because at the time of my fieldwork I was also the mother of a young child, and not long before this time I had been in the very same position as the mothers I encountered. Moreover, I have a background in public health, giving me a basic understanding of the health issues of newborns.

I was thereby able to follow along and engage in the clinical conversations between midwives and nurses. The familiarity of being 'at home' in my field thus allowed me often to be welcomed as more of an insider than an outsider.

During my fieldwork, I would engage in short conversations with the health professionals about the NDBS samples. In order to gain a deeper understanding of their perspectives, I subsequently interviewed seven of the health professionals I encountered during my fieldwork including three midwives, two nurses and two biomedical laboratory technicians. The interviews focused on their experiences with, and reflections on, the NDBS samples.

At the end of the working day, all of the NDBS samples are gathered together at the hospital and subsequently sent to and kept at the Danish Centre for Neonatal Screening at the State Serum Institute (SSI), a state-governed institute under the Danish State Ministry of Health, responsible for the screening and storing of the samples (Statens Serum Institut, 2020b). After the screening, the samples are stored in the Danish Neonatal Screening Biobank, a part of the Danish National Biobank (Statens Serum Institut, 2020a). I therefore continued my research by carrying out observations at the Danish Centre for Neonatal Screening, to gain an insight into the work with the samples there—e.g. how the samples arrive, what happens during the screening, and how the samples are handled when being put into the freezer. I visited the laboratory at the Danish Neonatal Screening Biobank twice and interviewed one of the senior researchers there who is also the principal investigator of several research studies utilising the Danish NDBS samples.

All interviews were transcribed, pseudonymised and thematically coded (Attride-Stirling, 2011), focusing on the practices of the samples, the work of the actors involved and what it enabled<sup>1</sup>.

### **Studying NDBS samples**

The NDBS samples are taken on filter paper, designed to absorb blood for later screening and storage. The filter paper is approximately 10 cm x 5 cm with three printed circles the size of a small coin. When the sample is taken, each of the three small circles have to be filled with blood. The fil-

ter paper is attached to two information sheets. One can be torn off and given to the parents. The other is to be filled out with information about the mother and the newborn, as well as information about when the sample was taken and by whom. This information is based on the Danish Central Person Register (CPR) number. The CPR number is a unique 10-digit number assigned to all Danish citizens either at birth or on migration to Denmark, and is used in almost all contact with public (and many private) services. Information from the individual's CPR number can be used for register-based research (Mortensen et al., 2006; Sortsø et al., 2011; Thygesen et al., 2011) where all persons alive and living in Denmark were registered. Among many other variables, it includes individual information on personal identification number, gender, date of birth, place of birth, place of residence, citizenship, continuously updated information on vital status, and the identity of parents and spouses. METHODS: To evaluate the quality and completeness of the information recorded on persons in the CRS, we considered all persons registered on November 4, 2005, i.e. all persons who were alive and resident in Denmark at least one day from April 2, 1968 to November 4, 2005, or in Greenland from May 1, 1972 to November 4, 2005. RESULTS: A total of 8,176,097 persons were registered. On November 4, 2005, 5,427,687 (66.4%). Besides being an effective identifier for clinical purposes, the CPR number therefore also serves as a major contributor to the Danish research infrastructure. Today, there are over 2 million Danish NDBS samples in the neonatal biobank at SSI. Following the primary purpose of screening, researchers can use the samples for research projects. All research projects using Danish NDBS samples must be approved by both the national research ethics committee and by the steering committee for the neonatal screening biobank (Nørgaard-Pedersen and Hougaard, 2007; The National Committee on Health Research Ethics, 2020). The estimated use of the Danish NDBS samples for research purposes has been documented earlier (Nordfalk and Ekstrøm, 2019).

## Care for families, quality and professions

In this section I will give an account of my field-work at the two hospitals, and how the practices I observed and the health professionals I interviewed shaped my understanding of how data and care are mutually enabling.

### **Professional care for families**

One day during my fieldwork at the first hospital, Marie (a midwife) and I arrived at a trendy apartment in one of the fashionable areas in Copenhagen to visit a baby girl, Ella, and her parents, Anna and Martin. After being offered coffee, Marie asked about the birth and how they were all doing. "What was it like to come home as a family of three? And how are we doing on getting some rest?" Anna answered that they were surprisingly relaxed and that the first days had been going well. I looked around their open kitchen, and wondered if they had done a lot of cleaning just prior to our visit or if this was just their standard home maintenance level. Marie later told me that she thought Anna looked more exhausted than she was admitting to being. This made Marie wonder if she should call her in a few days to make sure Anna was settling into her new role and learning how to rest with a newborn. Anna and Martin left the hospital the same day as Ella was born. As the NDBS sample has to be taken between 48–72 hours after the birth, some families are visited by the midwife after the birth, instead of their having to return to the hospital. A team of midwives will have a day away from the hospital for visiting a round of approximately five families, all of whom will have had a newborn two days previously. Therefore, the clinical aim of Marie's visit was the screening of the newborn. While observing Marie taking the NDBS sample, I was struck by the level of compassion and care that was expressed. Marie asked Anna to sit with Ella in the bed and breastfeed while she took the sample. Marie then crawled over the bed and placed herself in the corner besides the queen-sized bed. She squatted down in the tiniest space between the edge of the bedframe and the end of a radiator. Here she reached for Ella's foot without disturbing mother and child. After making a small pin-prick

in the heel with a special instrument, Marie gently placed Ella's foot on the filter paper, allowing the drops of blood to fill the circles. While taking the test, Marie was simultaneously observing the breastfeeding and talking to Anna. After the circles on the paper were filled, Marie crawled back over the bed, and put the sample in her midwife bag in the kitchen. During this visit with Anna and Martin the atmosphere that filled the rooms was not one of clinical purpose or of collecting samples as a tool for screening and research, but one of care. Care for the child and care for the family. As mentioned, the care the midwives provide is not something they have, it is something they do.

What I learned here was also that the aim of Marie's visit really was twofold: the midwives are interested in keeping up with the family and making sure they are doing well. As a profession, midwives are trained in pregnancy, labour, birth and the post-birth period. However, in recent years, there have been major budget reductions to the work of the midwives in all areas, and particularly for the post-birth period. Today, mothers of newborns who have had what is called an 'unproblematic birth' are expected to leave hospital within a maximum of six hours after giving birth. Much to midwives' chagrin, they are most often no longer in contact with the newborns or their families after they leave the hospital. Instead, a nurse specialised in newborns and childcare (in Danish: 'sundhedsplejerske') takes over the care of the family and visits them a number of times within the first year of the child's life. Therefore, the aim of the midwife's visits is both the actual clinical screening of the newborn baby, but very much also a professional aim of protecting and caring for the new families in this, their last, chance to see the family and the newborn. The midwives consider one of their finest tasks is to ensure not only a safe birth, but also a safe start as a new family. Therefore, the NDBS samples also play a more political a role. As another midwife, Emilia, stated:

And I think there's a huge value in them [the families] coming to us to have the sample taken. Because there are many conversations you can have in that exact period of time. While taking the sample, you can ask, 'How is the breastfeeding going?' Or in some way it's an occasion where they come to us and you can talk to them about

other things at a very vulnerable time in their lives. Otherwise there isn't anyone asking, 'Wait, you look really tired, have you even slept after the birth? Or why are you sitting so unevenly on the chair—is it a haemorrhoid or what?' Because it is not anyone else's job. So in that way it's also an occasion for connecting. (Emilia, midwife)

As the quotation from Emilia reveals, the care is evidently directed at the parents. From my observations I continuously experienced health professionals, especially midwives and nurses, going out of their way to make sure the parents and the newborn were cared for. One example is midwife Marie, crouching in small corners to take a sample without disturbing mother and child during breastfeeding; another example is health professionals patiently answering new parents' anxious questions about every aspect of life with a newborn, or having conversations to help support both mothers and fathers in their new roles. Yet in what Emilia says in the above quotation, another form of care is also expressed – a care for her profession. Midwives (and in this, some of the maternity nurses too) are uniquely trained in talking to mothers of newborns about the physical and emotional experiences just after having a child. And if they were to no longer be responsible for taking the NDBS sample, the midwives would no longer have a systematic reason for seeing the family after the birth. It appears that the care the midwives are eager to give the families does not constitute a legitimate reason for being involved after the birth, but the clinical purpose of screening does. Even though this aspect of the sampling of the NDBS is in many ways political, for Emilia and many other midwives it is also personal. Caring for the new families is sometimes the reason they became midwives (I was surprised at the number of midwives I encountered who did not have a desire to be in the actual delivery room). Having to take the NDBS sample therefore enables health professionals like Emilia both to care for the families and to care for their profession. The midwives thereby enable the NDBS samples as clinical and research data, and at the same time the sample mutually enables an access to the families, where the midwives can practise their profession while collecting the sample. The enablement is mutual.

### **Professional care for quality**

The midwives are not the only profession responsible for taking the sample. As explained, biomedical laboratory technicians also take NDBS samples on their daily rounds in hospital. For them, the NDBS samples enable another kind of care. As the biomedical laboratory technician, Sarah, said:

Let me put it this way. The newborn screening samples are nicer [Danish: hyggeligere] somehow, because it's small children and relatively healthy children for once (...). Because the parents are often these sweet people and they are happy because now they have their baby. In a way, it's nicer compared to the other parents, who are nervous and don't know if their child is ill, and [are worried about] all the tests they have to go through. (Sarah, medical laboratory technician)

Sarah expresses how the sample enables a small but enjoyable space for herself and her peers. Being a laboratory medical technician implies taking samples from all sorts of patients from all around the hospital. They encounter many people who are ill, and in cases where there are children involved, a lot of anxious parents, who are dealing with the (potential) disease of their child, and meeting Sarah for a test could be the answer that they are fearing or hoping for. Even though an NDBS sample is in many ways 'just another sample' for the medical laboratory technicians, for Sarah it enables a small space of joy. Another laboratory medical technician whom I observed during my fieldwork, a young man named Phillip, had a different approach to taking the sample than that I had seen when observing the midwives. He did not express the same level of care towards the newborn children or their parents. It was not that he did not care, but the care he was providing was directed at the sample. If an NDBS sample is not correctly taken – the circles are not complete, or there is not enough blood in each sample for it to soak through to the other side – the sample will be returned from the SSI and a new sample will have to be obtained. And I have to admit: the samples collected by Phillip were the most complete samples I witnessed. He was so careful that every step of the practice was done perfectly; and each of the samples he took (one day he did eight in a row) was done to a very high level of accu-

racy. This was his way of caring. A care for both the quality of his own profession and for the newborns, as he thereby ensured they did not have to have the sample taken again.

### **Enabling care and enabling data**

Studying the health professionals taking the NDBS sample, I found that care was enabled in several ways. Who or what was cared for, was highly contextual and actor-dependent. The midwives, nurses and biomedical laboratory technicians I encountered were unaware of the research conducted using the NDBS samples they were creating. Before I started my fieldwork, I would have expected that the health professionals who take the sample would be knowledgeable about what happens to the samples afterwards. After my fieldwork I now understand why so little attention is given to the afterlife of a sample. At times there is barely enough time to give the right amount of attention to those who need it the most – the parents and their newborns. Therefore, the health professionals here would not consider themselves 'data workers'. They are 'care workers'.

Yet, from the viewpoint of the samples being used as data for research, this is where the newborn children become 'data subjects' – and in this case, a preceding state for becoming a 'research subject'. At the hospitals, data were nowhere to be found. None of the health professionals ever mentioned data in relation to the newborn or the sample, neither in conversations with the parents, each other or with me. One explanation for this could be the distinctive detachment between the hospital setting where the samples are taken and the State Serum Institute, where the samples are screened, stored and possibly re-used for research purposes.

At the end of every day, the NDBS samples, no matter who took them or where, are gathered in a specialised envelope marked 'Samples from newborns.' I consider this the first step in the 'populationisation' (Holmberg et al., 2012) of the samples. Despite having their blood and thus their DNA on their sample, the individual newborns are no longer a 'part' of the samples. The only thing still attaching them to their sample is the CPR number listed next to their sample. The blood has been transformed from being a part of a newborn

human to a few drops on a filter paper. Through the caring work of the health personnel, they are now a segment, specified by the day they were born, on the way to becoming a part of a larger population of NDBS samples in the freezer.

### **Care for screening and populations**

Each night, a car drives from the most northern region of Denmark through the country, stopping at specified pick-up locations to collect patient samples from several Danish hospitals. Some of them are the envelopes with the NDBS samples. Other samples are collected by special service cars, sent by mail or flown in from Greenland and the Faeroe Islands. The Danish Centre for Neonatal Screening screens the NDBS samples from every day of the week except Sunday, thereby screening an average of approximately 210 samples a day. A team of biomedical and chemistry technicians open the envelopes in a laboratory at the Danish Centre for Neonatal Screening. The first procedure is to detach the sample from the paper with information on the child and mother to ensure anonymity. Then each sample is given a sticker with a code and the piece of paper with the CPR number is given a sticker with an identical code. The code is a mix of the date the sample was received and a randomised number. The paper with the information about the child and mother is then taken upstairs from the laboratory, where the data on the child and mother are entered into a computer and connected to the code on the sticker. From that point, the sample can only be identified through the code. The actual filter paper with the blood sample stays in the laboratory, where five small puncture holes are made in the first of the three circles of blood for the primary screening procedure. Each puncture hole is 3.2 mm diameter. Taken together the five holes correspond to about half of one circle. These small punctured pieces of sample-paper are what the technicians use to run the primary screening tests. In the case of a sample being screen-positive for one of the 18 disorders the children are screened for (Statens Serum Institut, 2019) a secondary test is performed. It may be either a more advanced test or a repeat of the primary test for that particular disorder. The primary screenings are performed as biochemi-

cal tests, whereas some of the secondary tests are genetic testing focused on the gene relevant for the disorder.

During my fieldwork, I visited the laboratory where the samples were screened twice. Especially the first time, the technicality of the screening amazed me. Here I gained the impression that the biomedical and chemistry technicians in the laboratory were very pleased with the machinery. They enthusiastically explained to me what each machine was able to do and what it meant for the screening process – often in phrases where one abbreviation did something to another abbreviation so I had to ask how to understand it in lay terms more than once. And they would kindly explain how the coating of the glass in the 96-well plate would make specific proteins stick; and, moreover, how that could help detect some of the diseases in the screening programme. I got a sense that they were proud of their work and genuinely cared about the newborn screening programme and securing the health of the newborns. This care was not directed at the actual newborns who delivered the sample. Rather these workers cared that the screening programme and the tools they applied were the most optimal. They too cared for the quality of their work.

Afterwards, the samples, which are now the three circles on filter paper with five holes from the screening, are gathered up with other samples from the same day, and put in a freezer in the lab. Observing this practice and seeing the samples being put together with an elastic band around them was a very visual representation of ‘populationisation’ (Holmberg et al., 2012). It was a recognition of the process where one individual sample was now enrolled into a segment of what was not yet a population, but would become one in the future. Finally, the samples gathered in the freezer in the laboratory are taken to the larger freezer in the Danish Neonatal Screening Biobank where they are stored indefinitely, according to current practice. This is the endpoint for the majority of samples. It is also where the ‘populationisation’ is done – the transformation of individual items of data into population data with over two million samples in the neonatal screening biobank: this is where the ‘population’ rests. Furthermore, if the current practices of the NDBS samples continue,

this ‘population’ of NDBS samples will continue to grow and within the next 80 years cover every living person born in Denmark, as well as a part of the deceased population. Thus, this biobank ‘population’ in effect represents a synthesis of being both complete, and yet still growing.

As to the samples in the freezer, some are used for research projects. It is also possible to do research on the samples in conjunction with the screening, even before they are put in the freezer. However, the majority of samples are frozen before being used for research (Nordfalk and Ekstrøm, 2019). In that case, the first step for the researcher is to gain approval to use the samples from the national research ethics committee as well as by the steering committee at the neonatal screening biobank. In order to obtain approval for the research project, a detailed description of the diseases, biomarkers and genes necessary for the project as well as clear estimates of the number of samples that will be used are required. After approval, the researchers are expected to hand in a list of CPR numbers to the SSI who will identify and supply the samples required. However, there is a maximum of how much of each sample can be used for research. A part of the sample must always be saved for the person whose blood is on the filter paper. Today, the use of samples for research is registered. Yet, as this register has not been updated with previous research, every sample is still manually checked to see if there is enough left in each sample to be a part of potential future research. If there is enough blood left for the sample to be used for research, a new punched hole will then be made in the second circle of the sample. The research analysis can either be carried out at the Danish Neonatal Screening Biobank, at other Danish institutions or in approved countries abroad, depending on the type of analysis and the research needs. The analysis will lead to new information, new data. When this information is handed over to the researchers, they can begin their study. For the researchers ready to start working on the data, the practices described, the actors involved and the care the data have enabled is not relevant. To them, the data are ‘raw’ and ready for new research. I interviewed one of the senior researchers at the Danish Neonatal Screening Biobank about the use of the samples

for research purposes. In his answers, he focused on the importance of population, as he explained to me:

With genetic variations, there is really a lack of these population-based studies, where you say you have a completely normal population and then some that are sick. Then, what is really the difference? You might say there is a fifty-times greater risk if you have this genetic variation than if you don't. However, if you do not have a population-based control group, you risk getting the wrong number. [...] You really need to have some population-based controls. (Senior researcher, Danish Neonatal Screening Biobank)

As one of the senior researchers at the Danish Neonatal Screening Biobank and chief managers of the Danish Centre for Neonatal Screening, he clearly cares for the health of newborns. In the rare cases where they do find a positive test in the screening process, it is extremely important that the individual child is quickly identified, contacted and given accurate treatment. This is at the heart of a screening programme. However, as a researcher, he cares for the *population* of newborns. Without the population, it would not be possible to produce valid and significant estimates on risk. Without the population of Danish NDBS samples, a unique research project like the iPysch project, which studies the genetic variations in newborns and how these relate to mental disorders (Pedersen et al., 2017) would not be a possibility.

Finally, if all of this begins with a newborn, then where does it end? There is no one answer. The physical materiality of the sample, besides the puncture holes for screening and possible research, ends up in the freezer at the Danish Neonatal Screening Biobank in Copenhagen. If the sample is a part of a research project, then where does it end up? In one respect, it ends up as knowledge; knowledge derived from the research done using the NDBS samples; knowledge that contributes to the progress of public health. Finally, the data that come out of the research projects with genetic sequencing are currently stored on a supercomputer called Computerome (National Life Sciences Supercomputer Center, 2020). On this computer, the blood from newborn

babies is now considered data and the newborns have become samples that have become population research data.

## Conclusions

In this article, I have shown *how* newborn babies become research populations: the practices, what kind of work is required, and what is enabled through the careful work of multiple actors in a complex, yet functioning, infrastructure. During my fieldwork, I found that the link between newborn baby and research data was much more my academic interest than it was an interest of the actors involved. For the medical staff taking the samples, there are no data: just newborns, parents and patients. For biomedical and chemistry technicians screening the samples, the focus is on the efficiency of the screening. While for the researchers using the sample for research there are no individual babies: only multiple samples and data. The physical, professional and ontological distance between them separated their understanding of the work they were doing as part of a larger infrastructure. However, this disparate and distant organisational data work does not hinder either care or an efficient creation of data. On the contrary, even with this fragmentation of care, the infrastructure is effective. Moreover, it is in the best interests of the newborn babies to be considered as individual newborn babies when the samples are taken; but not to be considered individual newborn babies when their samples are used as research data. In both cases, it ensures that the babies are cared for either through physical and emotional care, or through the anonymity of a population.

I argue that creating a national research population from newborn babies is possible through the mutual enablement of research data and care. Research data are enabled through care and conversely, with a mutuality, data enable care: care for families; care for professions; care for screening programmes; and care for population research. The notion of healthcare as an enabler for research data is well known. Nevertheless, in this case, the care enables more than just *some* research data. It enables a national population of research data. Creating population data from newborn

babies at a national level depends on the existing work, practices and infrastructures of newborn screening. National screening programmes enable the makings of a national research population of samples and 'populationisation' enables samples to become data. For newborns to become data, a population of newborns is needed. The sample of just one newborn is not data. However, the 'populationisation' of newborns with other newborns through their samples creates population data.

Mutually, the creation of population data enables care. The practices of taking the NDBS samples enables the midwives to systematically care for the newborns and the families after birth. The given timing of the NDBS samples, two to three days after the birth, enables the midwives to practise 'professional care' for families in the postpartum period. For the medical laboratory technicians, the samples enable them to care for the personal and professional quality of their work when handling the samples. Finally, the samples enable researchers to care for the population by creating new knowledge that can improve our public health. Thus, it is in the mutual enablement of research data and care that newborn babies can become national research populations.

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## Notes

- 1 This type of research (interview-based and without biological material) is not subject to ethics approval in Denmark.