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Report for the use of the Genome Centre working group

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Abstract

This report presents research findings from eight focus groups that discussed genomic data, their diverse uses, the risks and expectations associated with the data, and the establishment of a national Genome Centre. The discussions were held in four locations in 2017. The participants were people in different age, population and occupational groups. The concept of genome was unknown to many of the group members, but after having learned about it, almost everyone considered genomics research and the use of genomic data in healthcare to be a good thing. It was thought that genomic data can help to achieve better health and promote the common good. However, the discussions did not support the view that Finns would only be happy to give their data unselfishly for any kinds of uses. Motives for supporting genomics research were linked, in particular, to people's own experiences of hereditary diseases. It was hoped that genomics research would help — if not the participants personally — then at least others in the same situation. The group members also set conditions and restrictions for the use of genomic data. In particular, the commercial exploitation of the data raised doubts. The return of benefits from commercial activity to Finnish healthcare or public health was considered especially problematic. It was also feared that inequality would increase and the healthcare system would have insufficient resources for the use of genomic data. Most group members hoped that they would be asked for their consent to the storage and use of genomic data.

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Tiivistelmä

Tässä raportissa esitellään tutkimustuloksia kahdeksasta ryhmäkeskustelusta, joissa keskusteltiin genomitiedosta, sen erilaisista käyttötarkoituksista, siihen yhdistetyistä riskeistä ja odotuksista sekä kansallisen genomikeskuksen perustamisesta. Ryhmäkeskustelut toteutettiin neljällä paikkakunnalla vuonna 2017 ja niihin osallistui ihmisiä eri ikä-, väestö- ja ammattityhmistä. Genomi-käsite oli suurelle osalle keskustelijoista vieras, mutta siihen tutustumisen jälkeen lähes kaikki kokivat genomitutkimuksen ja genomitiedon käyttämisen terveydenhuollossa hyväksi asiaksi. Ajateltiin, että genomitiedon avulla voidaan saavuttaa parempaa terveyttä ja yhteistä hyvää. Keskustelut eivät kuitenkaan antaneet tukea käsitykselle, että suomalaiset haluaisivat vain pyyteettömästi antaa tietojaan kaikenlaiseen hyötykäyttöön. Motiivit tukea genomitutkimusta kytkeytyivät erityisesti omiin kokemuksiin perinnöllisistä sairauksista. Genomitutkimuksesta toivottiin apua – jos ei itselle – niin ainakin muille samassa tilanteessa oleville. Keskustelijoilla oli genomitiedon käytölle myös ehtoja ja rajoituksia. Erityisesti tietojen kaupallinen hyödyntäminen herätti epäilyksiä. Erityisen ongelmalliseksi koettiin hyötyjen palautuminen kaupallisesta toiminnasta suomalaiseen terveydenhuolloton tai kansanterveyteen. Pelkoina olivat myös eriarvoisuuden kasvaminen ja terveydenhuoltojärjestelmän riittämättömät resurssit genomitiedon käytölle. Suurin osa keskustelijoista toivoi, että heiltä kysyttäisiin suostumusta genomitietojen tallentamiseen ja käyttämiseen.

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I den här rapporten presenteras forskningsresultat från åtta gruppsamtal där deltagarna diskuterade genomdata, olika användningsändamål för genomdata, risker och förväntningar förknippade med genomdata samt inrättandet av ett nationellt genomcentrum. Gruppsamtalen genomfördes på fyra orter under 2017 och i samtalen deltog personer från olika ålders-, befolknings- och yrkesgrupper. Begreppet genom var främmande för en stor del av samtalsdeltagarna, men efter att ha lärt sig mer om begreppet upplevde nästan alla deltagare att det är bra att använda genomforskning och genomdata inom hälsovården. Deltagarna ansåg att man med hjälp av genomdata kan uppnå bättre hälsa och gemensamma fördelar. Samtalen gav dock inget stöd för uppfattningen att finländarna altruistiskt är villiga att lämna ut sina uppgifter för alla möjliga former av nyttoanvändning. Motiven att stöda genomforskning har i synnerhet anknytning till egna erfarenheter av genetiska sjukdomar. Man hoppades få hjälp av genomforskningen – om inte för sin egen del, så åtminstone för andra i samma situation. Samtalsdeltagarna framförde också villkor och begränsningar i fråga om användningen av genomdata. I synnerhet kommersiellt utnyttjande av informationen väckte misstankar. Överföringen av nytta från kommersiell verksamhet till den finländska hälsovården eller folkhälsan upplevdes som särskilt problematiskt. Deltagarna bekymrade sig också för ökad ojämlikhet och för hälsovårdsssystemets otillräckliga resurser för användning av genomdata. Största delen av samtalsdeltagarna ville bli ombedda att ge sitt samtycke till lagring och användning av genomdata.

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TO THE READER

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— if not the participants personally — then at least others in the same situation. The group members also set conditions and restrictions for the use of genomic data. In particular, the commercial exploitation of the data raised doubts. The return of benefits from commercial activity to Finnish healthcare or public health was considered especially problematic. It was also feared that inequality would increase and the healthcare system would have insufficient resources for the use of genomic data. Most group members hoped that they would be asked for their consent to the storage and use of genomic data.

Karoliina Snell
September 2018

1 BACKGROUND

On 12 October 2016, the Ministry of Social Affairs and Health appointed a working group to plan the establishment of a Genome Centre. The Genome Centre was tasked with creating national genomic, reference and variation databases and enabling the efficient use of databases in patient care, research and product development. Given the nature of genomic data, it has been considered important that ethical principles be confirmed for their use, and that legislation protecting the proper use of the data be laid down. The working group felt that the drafting of statutes should be grounded in information about how Finns and people using Finnish health services relate to genomic data and their various uses, how they understand ethnical issues, and what they identify as the greatest risks or opportunities brought by genomic data.

There are still very few wide-ranging research findings on Finns' experiences of, and attitudes to, genomic data. However, research data exist on the attitudes of the population, citizens and patients to biobanks, secondary findings, and the use of health data (Snell et al. 2012, Snell 2017, Snell & Tupasela 2012, Sihvo et al. 2007, Aktan-Collan et al. 2013, Tarkkala 2012, Raivola et al. 2018). At the working group's initiative, a qualitative sociological study on people's attitudes to genomic data was carried out. Karoliina Snell, D.Soc.Sc., of the Faculty of Social Sciences of the University of Helsinki, was responsible for the study. Snell implemented the study together with Henna Attila, M.Soc.Sc.

This report presents the principal research findings that help not only in bill drafting, but also in building sustainable and well-targeted communications. The results of the study conducted through the focus groups also provided a basis for planning the public events held in autumn 2017. The focus group material is extensive and will be used for publishing both domestic and international articles.

2 GROUPS AND PROGRESSION OF THE STUDY

The study consisted of eight focus group discussions in four localities: Helsinki, Vantaa, Jyväskylä and Oulu. Four groups met in May, two in June and two in September. Focus groups are common in qualitative social science research as a research method that can be used, in particular, to approach topics that are difficult or new for people (Wellings et al. 2010, Krueger & Casey 2009). For example, ethical questions and perceptions of new technologies are harder to approach by means of questionnaires or individual interviews. The groups serve as a place and situation where participants can weigh and consider their own opinions. The groups can also provide their members with information and background materials as a basis for discussion. Qualitative research and especially focus groups do not seek representative and generalisable results. Instead, they seek and identify, for example, expectations, fears and sore points. Thus, the study did not aim at wide population coverage, nor does the focus group as a method strive to provide statistically valid data. The discussions bring out ideas held by various people and groupings, as well as the grounds for their views. They also reveal how these views are linked to people's daily lives. The groups are a kind of experimental setup for discussions between people, where opinions are formed about a new, and perhaps even controversial issue. In groups, people talk with each other and reflect their own life experiences concerning the topic of discussion. Such information is difficult to obtain, for example, through questionnaires.

The groups were assembled to represent different population segments or groupings. People with a common background factor (occupation, stage of life, etc.) can communicate well with each other and feel they are equal partners in the discussion. By using different groups, the aim was to find a polyphonic view on the uses of genomic data both from laypeople and from people who have some sort of occupational relation to genomic data (nurses and teachers of biology and health education). Table 1 shows the principles for recruiting group members, the localities and times.

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Table 1.

	Recruiting principle	Locality	Time
1	Parents of small children	Helsinki	May
2	Students	Helsinki	May
3	Nurses	Jyväskylä	May
4	Unemployed	Jyväskylä	May
5	Teachers	Helsinki	June
6	Unemployed	Vantaa	June
7	Young adults	Oulu	September
8	Recovering intoxicant abusers	Helsinki	September

The recruitments were carried out using multiple channels and means. Students were recruited personally in the premises of the educational institution, the parents of small children and young adults through a Facebook group, teachers by email, unemployed people and recovering alcoholics through organisations, and nurses through a hospital. The groups had a total of 44 members, of whom 29 were women and 15 men. The average age of the group members was 46 years. The youngest participant was 20 years old and the oldest 62 years old. The groups included people with a Russian, Estonian or Sámi background. The group sizes ranged from four to nine participants. When people were recruited, the subject attracted interest and curiosity rather than rejection or suspicion.

All of the groups were moderated by Karoliina Snell. Henna Attila served as a research assistant and was present in five groups. The moderator's task is to bring stimuli and information to the discussion and ensure that everyone is given the floor. The moderator does not present his or her own opinions or views, but gives the speakers the opportunity to express their opinions. Nor is the purpose to teach people facts or correct their views. Instead, if a factual question is posed to the moderator, the moderator can give a brief answer without valuing it.

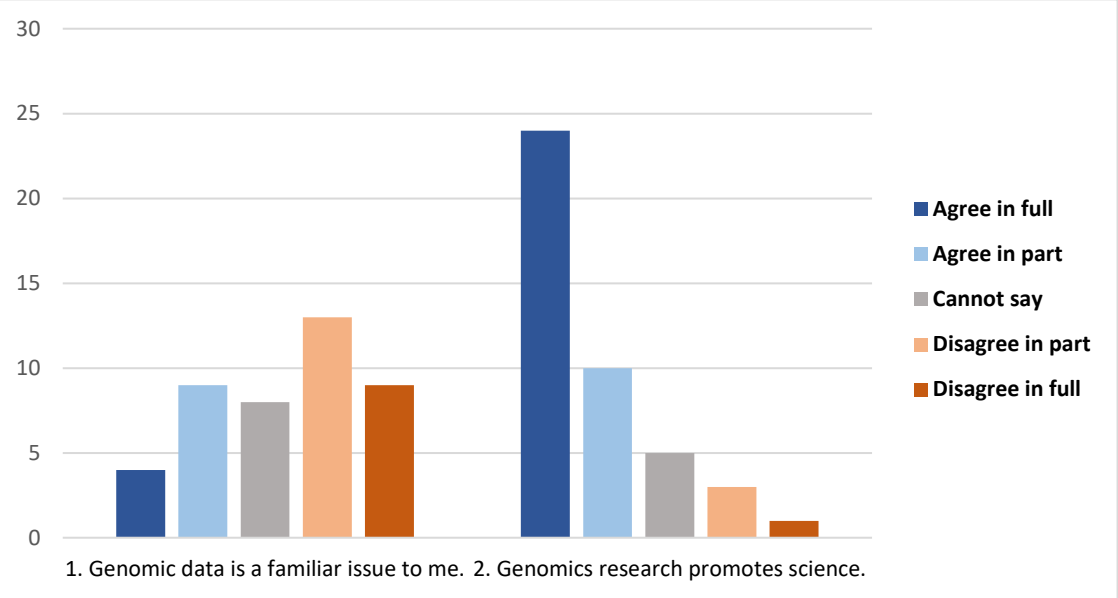
The group discussions started with the completion of the consent form and the background questionnaire, after which all of the participants presented themselves and explained why they were interested in taking part in the discussion. This was followed by a brief discussion on the participants' knowledge and experience of genomic data and heredity. The participates then read a short text about genomic data and their various uses. The text was taken from the Genome Strategy.

Thereafter, the members talked about the thoughts evoked by the text, and the various uses of genomic data and their collection methods were listed. The discussion then moved on to the establishment of the Genome Centre, the willingness to store one's own genomic data in the Genome Centre, and various consent alternatives. The final aspects discussed were the management of genomic data, one's own willingness to use such data, and the combination of various health data.

3 ADVANCE KNOWLEDGE AND PRECONCEPTIONS

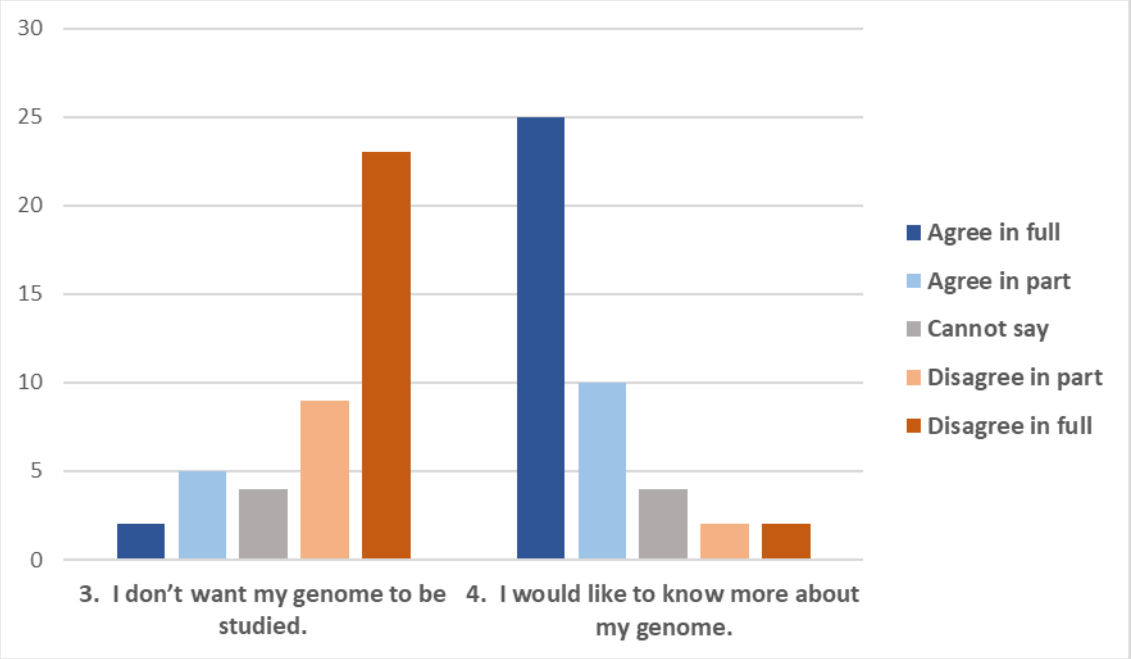
At the start of the group discussion, the participants filled in a form where they were asked to give their views on ten claims associated with genomic data. The answers to the question “Genomic data is a familiar issue to me” were a good indication of the participants’ knowledge level (Figure 1) Many were completely unfamiliar with genomic data, but mostly the answers moved in the field of uncertainty, i.e. the respondents were uncertain of the meaning of genomic data but had some notion — genomic data must somehow be related to genes or heredity. Based on this notion, people concluded that “Genomics research promotes science”, as most respondents agreed with the claim in full or in part (Figure 1.).

Figure 1. Knowledge of genomic data and promotion of science.



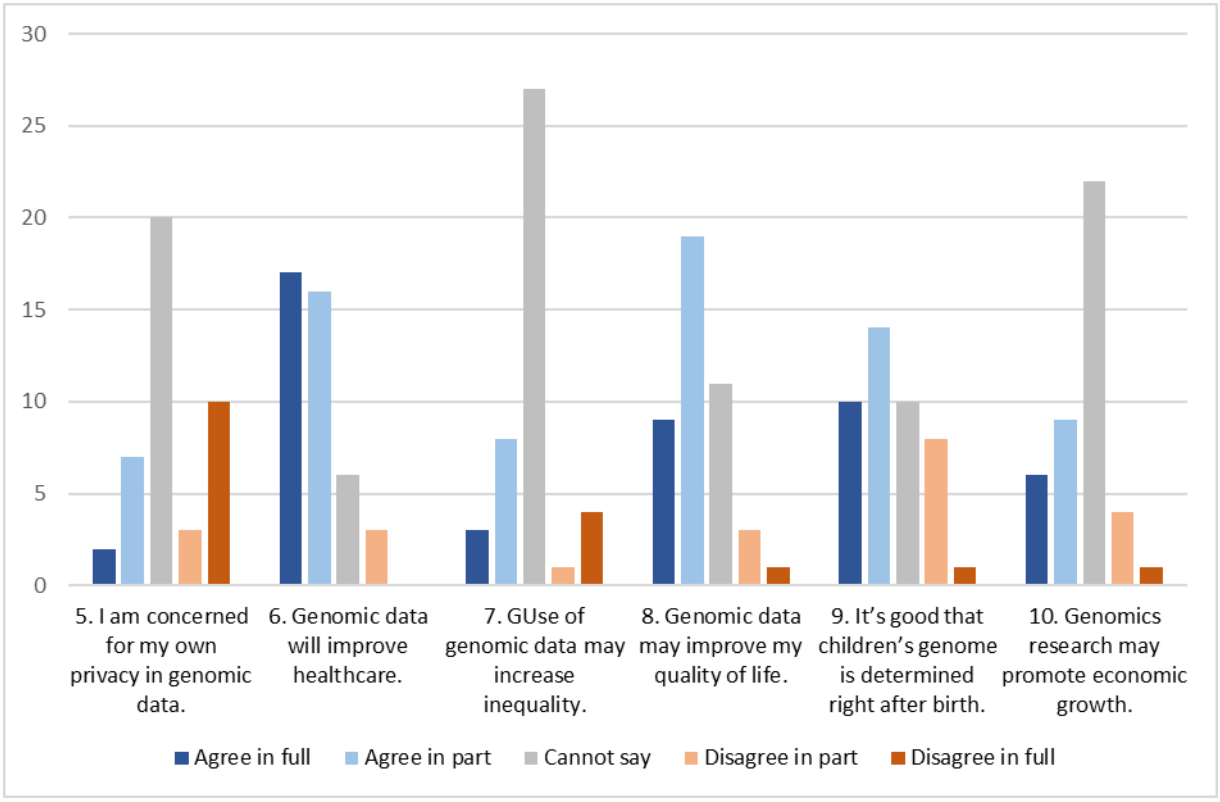
As a rule, group members were also interested in knowing about their own genome and were willing to have their own genome studied. Only a few participants did not want to know more about their own genome (Figure 2.).

Figure 2. Willingness to have one's own genome studied and to know more about one's own genome.



Group members also believed that genomic data will improve healthcare and their own quality of life. However, the belief in improved healthcare was stronger than the belief in improved quality of life for themselves. Most "Cannot say" answers came to questions about privacy protection, inequality and economic growth. The attitudes to determining the genome of children were fairly positive, but this question clearly divided the group members (Figure 3.).

Figure 3. Expectations and concerns in the use of genomic data.



4 REASONS FOR PARTICIPATING IN THE FOCUS GROUP AND KNOWLEDGE OF GENOMICS

The discussions started with a presentation where the participants talked about why they were interested in joining the group to discuss genomic data. Many participants reported that they themselves, their relatives or close family members had illnesses that are or may be hereditary, which is why the topic interested them. Some had also been inspired by more general interest in family roots. For many, the reason for participation was curiosity or the desire to know more about this topic that seemed unfamiliar but important. In addition, especially in the groups for unemployed people, group members said openly that the €20 voucher granted as a participation fee had attracted their attention. People in the nurses' and teachers' groups considered the topic important and their own knowledge partly inadequate, for which reason they wanted to know more about this issue. But also in these groups, the personal and family health history proved to be a major motive for interest in the genome. For communications, it is important to note that the people selected for the discussions are easily those who have some experience of hereditary diseases and related discussions. It is harder to reach people who do not have a personal interest in understanding hereditary diseases or in improving their own health or the health of someone close to them.

> "R1N5: And my mother came down with ovarian cancer a couple of years ago and her gynaecologist said that it'd be worth checking and then I said it to my own gynaecologist and, well, it didn't go any further and I was sort of, um, wondering what to do. Actually from then on, it's like all of the women in the family have got cancer, or most of them."

> "R6N1: My son has epilepsy and as, see, it's in my mum's family somewhere, and I'm interested in how it goes, could it somehow be prepared for, that it jumps, like, over a generation then."

> "R8N1: See, I've followed quite a lot on the telly, like, I got interested. And I've inherited some illnesses from my father and mother, so for that reason."

> "R4N4: Really interesting to get information about our roots, somehow."

Most participants said that the concept of genome was unknown to them. They knew what genes are and on many occasions, they spoke fluently about heredity, individualised treatments, even epigenetics and, for example, genotypes and phenotypes. For communications, it is essential to be aware that the concept of genome in particular seemed troublesome. If a concept is unfamiliar, merely using it in a sentence is difficult even if the speaker would understand a good deal about heredity and genetics.

> "R7N2: So I didn't know anything, this is the first time I was asked to be in this kind of study, so just for that reason I thought I'd go, and I want to hear what it is, 'cause I really don't have anything, well I have a bit of a clue what it might be connected with, but really I'm starting out pretty much blank."

> "R1N1: I'm mixed up now, what's a genome and genes, what's the difference, but I'm not, if the talk is about genes in general, well I know something about that, what I remember from school, but nothing special."

Thus, many had experiences of hereditary illnesses and some had participated in related scientific studies, while some had undergone diagnostic genetic tests and some had given their samples to the biobank.

> "R2N1: Well, I know a bit about this genomic stuff, we had, hmm, in autumn, some sort of sampling event there at a location, I went there to give a sample myself, I think it went to some gene bank, this sample."

Although the genome and the use of genomic data were not previously familiar, it was easy for group members to start talking about these issues after they had received some supplementary information. Previous knowledge, experience and perceptions of heredity, illnesses, healthcare, research and medicine were applied to genomic data. The groups also discussed how much various diseases and characteristics were hereditary and how much they depended on environmental factors. Several groups discussed the heredity of depression and mood disorders and how the related genomic data affect people. In the group of recovering alcoholics, the consensus was that alcoholism is not genetic but a consequence of the growth environment.

All of the participants wanted more information on heredity and the effects of genes, and how, for example, lifestyle or other means can influence the outbreak of diseases. The nurses and teachers contemplated the limitations of their own knowledge levels and were aware that they needed to update their knowledge in terms of the basic principles and application of genomic data. One nurse commented on her own skills and the need for training as follows:

> "R3N8: And I have to say, that I at least haven't felt that my employer would've provided all that much training in this, that I've had to dig for information myself . And then I've tried, like in my work community, to feed something to somebody if there's been anything. But if some tests have been done, that some gene is sought, then it's up to me, do I understand to look up, well, what it is, what I order from Weblab."

Especially in the teachers' group, the need for information emerged at many different levels, not only in their own decision-making. The group discussed, for example, whether Members of Parliament have enough knowledge and understanding when they make decisions regarding the Genome Act.

> "R5M2: Well, at the stage when the bill goes to Parliament, well, the MPs are a motley group of people, so, what kind of understanding do they have of things, and yet they're the ones that approve or reject the law.
>
> R5N2: Um, it might be somehow badly split then regarding how... In the same way as with gene-modified food, it may be that all is seen as very black and white."

5 EXPECTATIONS AND CONCERNS

5.1 COMMON GOOD, OWN BENEFIT AND THEN THAT COMMERCIALISM

Most participants felt that the use of genomic data in scientific research and healthcare was a positive opportunity. There was the desire to promote science, research, health and the common good, and it was felt that this could be possible by studying and using genomic data. Since most participants saw the utilisation of genomic data as important and promoting wellbeing, the majority was also ready to give their own genomic data for the public benefit.

> "R4N3: Yep, I'm ready at least to support studies always."

> "R2N1: Me, too, I'm positive about being able to use it also, for the benefit of close family and then in my opinion for the benefit of society anyway."

> "R5M2: Quite OK, if there's some benefit in it."

The common good was regarded as highly important, but it was also seen that genomic data included opportunities for the promotion of one's own health and thereby for one's own benefit. It was contemplated how the data could be useful to both oneself and others. Nearly all of the participants were somehow interested in receiving information about their own genome, and many also talked about the possibility of utilising the data. Group members spoke about prevention and lifestyle changes, as well as general curiosity about one's own genome and family background. Some saw the benefit of genomic data so that the outcome could speed up their access to the doctor.

> "R1N2: "Hmm, on the same lines, yes. And it came to me like this, that I think this would really be beneficial, that when these begin to be studied from people, that at least for myself this kind of fact data prompts me to exercise and eat healthier, when I get some data about myself, that isn't just pulled out of thin air... something just, and try it out, maybe this works."

> "R1N3: 'Cause I've sometimes, like, wondered if I'm the same as my dad... then when I became the same age as him and began thinking about my own, like, mental health issues, personal, at that stage I started to think a lot about

> how hereditary they are. I noticed that I'm just the same as my dad, like, from this specific point of view... Yeah, I'm really interested in everything, how, like, humankind could be helped by this field."

> "R2N2: Yes, that would be really nice. And also, like, even, how many of this kind there are, for instance like me, in certain things or like, that it could be quite interesting."

On the other hand, a question was raised as to whether genomics would bring some new understanding about their own heredity, which is already known to many through various hereditary predispositions.

> "R5N1: Well, in some way, in principle I think I could do it, that it, like, wouldn't bother me, that in my opinion it would be interesting. But then, the results, so how would they affect my everyday life, like, somehow I doubt that they would have all that much impact. And even now, when I see a doctor, the doctor always asks about my parents and grandparents and, like, what genetic factors in a way are there. So, it's a bit like the same kind of thing, what runs in the family."

Although some doubted the significance and benefits of genomic data to themselves, the issue still aroused curiosity. The great majority of participants felt that genomic data, either now or in the future, could improve the understanding and promotion of one's own health, or simply the understanding of one's own background and family roots. In general, an individual's own benefit and the common good went hand in hand in the discussions, and they were seen to be mutually supportive. However, it is important to note that, especially among younger group members, the reception and possible own use of one's own data were often seen as a prerequisite for donating the data.

> "R2N1: Hmm. This is, like, how I see it, for my part it's okay to take data about me by all possible means, but then something has to come in my direction so that I can use it for my own benefit. That otherwise it's totally useless to me, and at that stage if I don't personally get any benefit from it, well, after that I wouldn't have any motive to give anything there."

Often the discussions underlined the importance of planning the Genome Centre and projects associated with genomic data so that they would primarily support people's health and wellbeing. Health should be "the spearhead that leads the way". Mothers discussed this aspect:

> "R1N5: When you think about all these from the angle of health, well, what I think is good, like, it should then go through various levels, and promote health, promote people's wellbeing, physical and mental, like that should be at the top there. And then if some economic benefit comes of it too, well, that is
>
> R1N2: A bonus.
>
> R1N5: yeah, a good thing, a bonus, but that in a way, like, what's the goal and what takes the lead here.
>
> R1N1: And those keywords, that is health and confidence, I mean confidentiality, they're, like, in my opinion what comes to my mind, what I count as important."

Promoting health and the common good were often set against business and commercialism. Commercial activity and doing business were seen as operating under a different logic and morality than public research or healthcare. It was felt that commercial activity always aimed at making a profit even when it had goals that promoted health and wellbeing.

> "R7N2: Well, that sounds really fine, that we could, just for people who are found to have some illnesses, that we could verify them... Somehow I'm sceptic. This sounds really good, but then there's this, that the place that would then own them, that it should be available to everyone, and not only one company that wants to make money on it, because it's so easy to take it in that direction then."
>
> "R2N2: That it's, like, the point here that if they were ethically acceptable and good projects, that would have these sorts of effects for the general benefit of people's health and all that kind of thing. But then if suddenly, like in a way often happens in life, that then these data are studied even further, and then some slightly unethical systems get access there. Some with their money get in between and whatever, like, maybe some sort of inequality arises."

Commercialism was connected with inequality, as well as with unethical behaviour, 'flimflam' offered to consumers, uncontrolled information and targeted marketing. Although people were well aware that for instance universities do not independently develop medicines, and economic growth is gained only through business activity, they did not trust that the pharmaceutical industry and private companies would aim primarily at benefits for everyone. Instead, people identified many potential risks and injustices.

> "R6N2: Oh right, who wouldn't be allowed to use them. Well, in my opinion, commercial bodies are perhaps one, there are some good commercial things, but it doesn't, well, when it comes to it, just taking money into the pocket, well it isn't like–
>
> R6N3: Yep, exactly, how is that then prevented, in the end, so it isn't channelled to them. That there should be people and bodies in between that operate very ethically and morally."

This type of tension was a thread running through all discussions. Benefits were seen in business as well as in cooperation between public and private actors, but the risks and uncertainties involved were sometimes felt to be greater than the benefits achieved. People wanted clear rules and control mechanisms for commercial activities, as well as the possibility to influence the use of one's own data. This could prevent the exploitation of people.

> "R3N9: In that sense, this kind of commercial cooperation and the rest can be a worrying thing, but if there's some real instance involved somehow, then–
>
> R3N8: Hmm, I don't have anything against it either, if Finland's economy for instance somehow got a push from it, that we have: Wow, what homogeneous material here, yippee! So, why not, but there should be some limits and ways to regulate it, so that they couldn't be sold just like that. And yeah, there they went as I didn't forbid it and restrict their use!"

The discussions repeatedly highlighted the difficulty of perceiving how the benefits come back to oneself, to Finns or to public healthcare when genomic data are used, for example, by an international pharmaceutical company or by a small unknown firm. Do Finns and the Finnish healthcare benefit, or does the company, in the end, only produce economic gain for its owners? It was also considered a problem that companies, almost free of charge, use the data collected in public services or donated by private individuals. It was felt that the operating models for projects carried out by both commercial operators and public-private partnerships were not transparent or understandable to ordinary people.

> "R7M1: As otherwise, too, it's been like the idea of businessmen in the 1990s and 2000s, to take information for free but sell it off at a big profit. And just take advantage of it that people don't understand that some party in a way just takes them."

Thus, commercialism was connected with inequality and possibilities of exploiting ordinary people. In the group of unemployed people, the moderator specified previously expressed comments on commercialism by saying "it seems that you are concerned about commercialism", to which one member of the group answered:

> "R4M1: That's because you're asking the poor and the unemployed about it... Commercialism worries the poor."

5.2 TRUST AND LEGISLATION

Confidentiality and openness were mentioned in all of the groups as the key principles and guiding factors when utilising genomic data.

> "R8M3: Yes and maybe it's mainly openness and confidentiality then, that's what I at least would hope for this genomics research. So that it doesn't wind up sort of in the wrong hands, for example personal data and such."

It was hoped that there would be clear legislation and operating models for the use of genomic data. It was felt that these could help to influence the practices of both the private and public sectors. It was considered that genomics research should be promoted, but the exploitation of data should not be taken forward too fast, as then the potential for misuse increases.

> "R3N7: Well, I don't know. Let's say that I'm sceptic in that, well, I'd like to trust and I've been more of the kind who trusts easily, but unfortunately then when exploitations occur, and then it's using people to benefit themselves, still. It's always happened, judgements on that are still passed. Well, people don't change, so just on that basis, in my view there should be enough restraints."

> "R2M1: At the outset I'd say yes to research, then we'll see how it proceeds from there. Now when it's not yet at that stage, so it's hard to say yet whether someone starts to develop these products, one step at a time first. That then if people get accustomed so that it's normal that there's research and it's used in healthcare, so maybe from then on it would be okay that there are, like, products and such."

Although the business world was considered definitely less reliable than the public sector, it came out clearly, especially in the two groups for unemployed people, that even public actors are not always trustworthy. Unemployed people had encountered many difficulties in their lives and felt that public actors had not been able to respond to these well enough. In consequence, it was thought that even if the aim is the common good, there is always an individual who benefits from it more than others. Even the state can do business on its citizens.

> "R6N3: One aspect of it, this doesn't mean that I think that just Sipilä is bad but it's these old-boy systems. That we've been terribly naive about things and
>
> R6N2: Yeah, and then when it's for a good cause, like this too is a good thing, this genomics research, but when it's for a good cause, then there's some hawk pulling it, yeah, that's what it is.
>
> R6N3: Yep, we should always remember that the dark and light, they're the whole, that everything has another side to it. But usually, it's just, like, forgotten and then it's thought that something's a good thing, and then it's noticed that, aha, that, too, ended up benefitting someone."

> "R4M4: The National Board of Forestry, too, was planned to be a government agency, or many others of them that are now private.
>
> R4M1: Yes, there's something fishy here. The state has recently sold their holdings quite vigorously. In which case it becomes business, our health data."

Monissa ryhmissä keskusteltiin mahdollisista yksittäisistä henkilöistä terveydenhuollossa, jotka voivat vuotaa tietoja tai käyttää niitä vääriin tarkoituksiin. In addition, some participants had negative experiences of healthcare. Therefore they felt that doctors or other healthcare personnel were not trustworthy in the use of genomic data, either. Information systems and their users were also recognised as risks. Past negative experiences of healthcare and information systems have a strong impact on the acceptability of new operating policies and systems.

> "R1N2: In the end, the question is how trustworthy the people are that promise trustworthiness. Well, in my opinion the leakage of the Kanta database shows that in general it's thought that the doctor's ethics, that it's like unbreakable, and that too has leaked."

> "R6N3: Well, these doctor experiences, these doctor experiences, that I've had here for years, lots of them are bad, that you aren't listened to, not seen, so, well, I'm not really sure. I was terribly open like they could know everything, but all things have turned against me. I try myself to be honest and open and aware, and everything has turned against me. So I don't know if I even want to have anything to do with healthcare anymore."

In general, however, most group members trusted the authorities, public healthcare and research, even though they were aware that all of them have individuals who do

not necessarily work according to the rules. The system is therefore not completely reliable. It was also considered a problem of the public sector that an individual employee or a public servant is not responsible for errors in such a system.

> "R2N1: Somehow the first thing that comes to mind is that some official body, but then again it tends to be a little like there, then, in a way nobody is responsible that, if it happens that information is misused, well, then it's a bit like, oops, this happened and then in a way there isn't anyone who it would be linked to. So it would have to be, yeah, like clear that the issue couldn't be swept under the carpet if mistakes happen there, but there would have to be some kind of absolutely trustworthy system, so that people really could be committed with trust."

The utilisation of genomic data was seen especially as a matter for the future. To be committed at present to the storage and use of genomic data in the future requires strong confidence in the bodies administering the genomic data. The system to which people will be engaged for decades must stand on a sustainable footing and its operations must be morally and ethically acceptable.

5.3 RESPONSIBILITY AND EQUALITY

Questions of responsibility — how the responsibilities between the individual and society should be defined with respect to genomic data — became a major issue in the discussions. Among the questions pondered was the individual's responsibility for preventing diseases and whether genomic data would affect it in some new way. Many thought that genomic data could be beneficial and could have a positive effect on their own lifestyles, while enabling disease prevention. On the other hand, opposite views were also expressed. According to these, genomic data would hardly affect lifestyles in any way.

> "R4N3: At least I don't, I don't believe that it would affect my life in any way. That I live in my own way and always strive to live healthy otherwise, so it has no effect. But I think it's good in that, if the healthcare service has the information, well, then if there are some symptoms, it can be checked right away could it indicate this kind of thing, so that some disease wouldn't be missed because it wasn't understood that it's in the genes."

Although the individual's responsibility came up in the discussions, the responsibility of society and healthcare for supporting the individual gained an important role in the discussions. The sentiment was that it can be difficult for an individual to understand

the content of genomic data and its significance for one's own health. Knowledge was also considered to be potentially so distressing that processing it calls for support. It was also argued that information that neither the individual nor society can respond to properly, and with the right kinds of measures, is unnecessary or even detrimental information.

> "R4N2: Well, it occurred to me first, that if for example some kind of gene study is done, it doesn't help the person any if it's just said that now there's this in your genes, that quite the opposite, it would begin to cause anxiety, that if some illnesses, cancers or mental health diseases, strike and I can't do a thing about it. That society should, like, be supporting in it, that they sort of there from healthcare right away, I don't know how but somehow to help, influence, that the disease doesn't break out."

Many groups stressed that the healthcare system and society should bear the responsibility for the information they create and maintain, and the responsibility for its use so that people are not left alone with that information. At the same time it was pondered how well prepared the healthcare system is for this.

> "R5N2: And then I thought also that, if I would get my own chart from there, and there would be some risk for something, well, then somehow, like, the readiness of the healthcare services, that okay, we'll take you into care for this and start to follow, then that would give something to the person and not just that here's the information and live with it."

Equality and polarisation emerged in all group discussions as a potential downside of the utilisation of genomic data. Especially the teachers' groups discussed in general how health gaps are widening and how difficult it is to influence them. It was suspected that if society and public healthcare cannot shoulder enough responsibility for the use of genomic data, health gaps may become even wider. It was additionally pondered that individuals have very different economic and information resources for utilising genomic data. Similar concerns were also raised in other groups, and especially the unemployed wondered if they would be able to afford the additional measures that genomic data may cause.

> "R5M2: Of course here now it was said that, okay, it will, like, get cheaper and be possible to buy and so on. And then maybe it will be like, those who have the money then they can do it, and then [sigh] would it somehow affect the rise of health differences. That those who have more information about this, then are also able to benefit better than those who have less information, like that."

> "R4N5: "Yeah, would it now become business, that what about if it was found that you have so many diseases, then can you afford to take part, like, go for examinations? Will they cost, will I have to go to the private sector? Won't the municipal healthcare reimburse it then?"

It was also considered important that the examination and storage of the genome should be voluntary and should not be a prerequisite for obtaining health services. In other discussions, it was argued that genomic data can also lead to coercive measures.

> "R1N5: That it...I think it would be really important that it doesn't become that everybody then is obligated to go for it, instead it could be some sort of extra that if you want then it's possible to go for it. And in connection with it, that it shouldn't be that some health services hinge on the genomics studies having been done, but that there should be equal, like, rights to get all healthcare service."

> "R7M1: But would it be, like, suggested that you could possibly have a need for this kind of thing, that it would be a possibility. Or is it so that it would be, sort of, compulsory to go? That it might be possible that others catch some disease from you, that now here comes this, like, intervention, that you go there, so, how would it be?"

5.4 ETHICAL ISSUES AND HUMANITY

The examination and use of children's genomic data was considered ethically challenging. All groups recognised the associated potential benefits while simultaneously contemplating the responsibility and ethical problems brought by the data. The groups held diverse discussions on what would be ethical and useful to tell as concerns the type of data, the recipient and the age of the child. Opinions were divided and also frequently changed during the discussion when the participants began to outline the many different possibilities for using genomic data. However, no one expressed a categorically negative view; instead, all felt that children of all ages and their families could benefit from genomic data. The groups also discussed the responsibility for informing relatives and the related ethical challenges. Also in this case, the participants identified many alternatives and their different consequences, and no clear consensus was reached as to what would be the right way to use or not to use genomic data for the benefit of relatives. However, both discussions highlighted the possible anxiety and feeling of guilt stemming from genomic data.

> “R1N2: In my opinion it would be a really good idea, like, to do this, but now that you put it that way, I began to think that you have this newborn baby and your head is all mixed up and then if tests are done on the newborn and your child gets schizophrenia, so how would the mother feel about bringing up the child, and am I doing something wrong and all that guilt and other feelings will certainly be part of the pattern, too. It’s a little risky, yes, to start with this kind of thing at the beginning.”

> “R1N1: That if, in a way, the good intention involved, improving life and, in a way, the benefit of calming down and guidance and prevention, so what if it then changes, in a way creating inequality, that is who can afford the cost, for instance, if the price is something like that. Or if you then feel yourself to be worse. There are always those situations, whether you are nursing or whatever you do, so it’s always wrong. Are you now a bad mother if you don’t have these tests done for your child, then tut tut.”

> “R5N2: Yeah, I think that as a mother myself, there’d be even more guilt that now the disease surfaced when I wasn’t able to keep it somehow at bay, though it was known.”

Some groups held long discussions about humanity. It was considered important that people are seen as a whole that is not defined by genes alone. It was contemplated whether the use of genomic data could lead to a wrong direction, when personality and life experiences would be secondary. Some groups also discussed whether the establishment of the Genome Centre and the investment in genomic data will take resources from health centres, whether health centre fees will rise and whether it would be better to invest in encounters with the patient and in human-centred services.

> “R6N3: If I had been listened to, and with my family history, my mother was, like, narcissistic, that is, a person with a personality disorder, and father did his best there in the middle. So, if such things had been listened to, then I perhaps could now have a foundation in order... that I could have left it more easily with the help of support. So now then they want to build this sort of research world instead of listening to people.”

> “R1N5: In my view, this comes to what is the concept of humanity. Of course, the ethical issues, too, but when I myself think that life should be lived, like, from within each individual, learning about yourself, about the person you yourself are, with your own characteristics. So, it would feel terrible then that something like that, like the factual genomic data would start to influence how I live, I wouldn’t go as though listening to myself to live this life but from the

> data what's there. So that life wouldn't become just a performance, which would, like, be measured on all scales."

In the discussions, ethicality was connected with good practices, support for the common good, health promotion, equality and a humane approach. Hurry, commercialism, self-interest and malicious people were seen as threats to ethical behaviour. General social development was also seen as a potential threat. It was pondered whether we can be confident that the existing trustworthy social system will prevail. It was thought that a large volume of new genomic data could lead to future operating models that would not be considered ethical now. What features can we start to prune and will there be a new wave of eugenics?

> "R5N1: I also thought, when I got this invitation, well, that quite a lot can be seen from those genes, for instance some aggressiveness or something similar, so what if it was, like, that everyone would be tested bit by bit, like breeding so that there would be less aggressiveness or fewer diseases, is that the case. Is that what you're trying to do?"

6 GENOME CENTRE, CONSENT AND ACCESS TO DATA

After discussing the various uses of genomic data and the associated expectations and concerns, the participants were asked whether they would be willing to have their data stored in the Genome Centre. The majority of group members had a positive attitude to this idea as well. For example in the group of nurses, many said yes, but some expressed more reserved views.

> "R3N9: Well, I suppose I would, I don't have anything against it.
>
> R3N3: Hmm, me too, yeah.
>
> R3N5: Yes.
>
> R3N6: Yes.
>
> R3N8: With reservations.
>
> R3N2: If it's that kind of centre that the government then administers, etc. and there are clear regulations, so yes, I guess I would give them my sample. But some kind of commercial cooperation, well...
>
> R3N5: Hmm. But yes, this will still need to be so-called marketed pretty well. I mean that, like, informing ordinary people who don't have even that much information like I have, well, they don't necessarily get it all at one go, that it will have to be —"

In general, young adults were ready to have their genomic data stored in the Genome Centre, but some reservations and conditions were expressed there, too. In particular, these were concerning the possibilities to control the use of one's own genomic data.

> "R7N1: Yeah.
>
> R7N2: Yeah.
>
> R7N3: Yes!
>
> R7M1: Like in principle. That I'd have the chance to decide expressly what it's used for, so the right wouldn't, like, transfer to the centre that could then do it. Like, that I'd be asked what it can be used for."

In the group of unemployed people, in addition to the general positive attitude, it was also pondered whether the data stored could produce information that is negative for oneself.

> "R6N1: Yes. Quite good.
>
> R6N2: I agree, it's OK, it's OK.
>
> R6N3: That also has the idea that if a person thinks that now there's this in my family, I can't have kids and if that influences it, then in a way it's negative.
>
> Moderator: But would you be ready to have your genomic data stored in the Genome Centre?
>
> R6N3: Not necessarily."

A similar discussion was repeated in all of the groups. Those who were the most eager immediately responded yes to the question. Thereafter, some expressed critical points of view. For example, the following were mentioned as obstacles to the storage of data: commercial operations and if the Genome Centre were a private organisation; if the data would not be released for one's own use or one could not decide how the data would be used; and possible negative consequences stemming from one's own genomic data. Thus, storage was immediately linked with the use of the data, and it was difficult to consider it as a separate question.

> "R4M1: In the case that it's government administered and that I have complete access to my data, in other words I refuse at this stage if it becomes private.
>
> R4M4: It could change to become private later."

As a rule, most participants considered it important that they are asked for permission both before genomic data are stored and before they are used for various purposes. It was felt that asking for permission is a good custom and is current practice in medical research. In addition, it was emphasised that the provision of data should be voluntary and people's self-determination should be respected. One group member mentioned her previous experience when she had been asked for consent to an umbilical cord blood examination.

> "R1N3: Yeah, I just have the feeling that of course, sign the form. And yet it felt good that it was said that hey, it's possible and you can refuse, you aren't obligated and I was, like, let's do it."

In particular, it was thought that if the data were to be used for commercial purposes, permission should definitely be requested, or such uses should even be prohibited by default.

> "R4N3: Yes, there would be consent for me, and then I started to think, too, that if there were some kind of law that these could be used only for healthcare purposes and to benefit people's health. That it would exclude business use, but I don't know if it's possible [laughs]."

> "R7N2: I agree that one should control the strings oneself, and be able to manage it."

In their group, nurses raised the issue of how screening samples taken at maternity clinics are transferred to the biobank by notification. Many contemplated the inadequacy of information and the justification of transferring the samples because they had not even known that the samples would be stored anywhere in the first place.

> "R3N5: ... I was just thinking that I, at least, don't remember that I would have been asked anything, that a blood sample had been taken from me, for that biobank. But it's so long ago.
>
> Moderator: Yes, now there's been a notice that these samples, which have been collected from pregnant women, it's an infection sample that, that HIV and others. And it can be prevented, a refusal can be made to the place.
>
> R3N5: But a person can't refuse if they don't know! That I didn't even know that, I thought that when a blood sample is taken, so they're examining just the blood group or HIVs and so on, and then it's thrown into the trash or wherever. I didn't think that they would ever, like, that I had no clue that just like something is taken from kids at birth, well, do they then go, too, do we have samples collected from how many without our knowing?
>
> R3N9: Like I've also been wondering, that I had my firstborn in '93 and I don't remember that I would have granted permission for anything —"

However, the wishes concerning the content, dynamism and scope of the consent varied. Many wanted themselves to determine where the data could be used. Some wanted to make the selections in advance while others thought that the permission could always be given on a case-by-case basis.

> "R2M1: Yeah, I've thought about it, that I could grant permission to use these as the default. But then in my opinion it would really be fair that there'd be some notice that this body intends now to use your data and that you have,

like, 14 days' time to refuse, um, the use of your data if you don't want to participate."

Many were also ready to give decision-making power to trusted experts as well. If, for example, the Genome Centre is perceived as a reliable expert body, it is assumed that it has expert people who are able to decide on the use of the data. However, many required that the consent be given initially to this expert body. Group members often referred to researchers who can make the right kinds of decisions.

"R8M1: I too would think that a medically educated researcher like that would know better how my genomic data could be used to benefit research, and I would give the power of decision then to the researcher, yes. That you've already given your consent once that it's collected into one place, so yeah, in my view, too, that's where the wise people are."

With regard to healthcare, it was felt that access to information should be case-specific — when the medical and nursing staff needs it. However, the trust shown in healthcare staff and information systems was not as great as the trust shown in researchers with regard to the use and secondary use of the data.

"R1N3: How with a shockingly serious face for instance healthcare authorities can say with a straight face. For example, I ticked all the boxes there on Kanta, denying looking at my affairs, so then I realised when I went somewhere to an occupational health doctor or occupational health nurse, that they hadn't, like, contacted me, that they had read them beforehand and then they were discussed even though I had all the ticks there, that they shouldn't have looked in advance. Well, then I noticed the same thing also in healthcare stations.

"R4M1: On a case-by-case basis and not without permission.

R4N3: Yep, I agree."

"R1N2: Well I guess if there's some medical issue, so the attending staff, with a separate consent, and I don't believe now that anyone else other than yourself necessarily has to have access to them, that yeah, you yourself I guess know how to give the information ahead to others then.

R1N4: So, with your own consent, then if some close relative wants access, then consent to that."

However, many participants stressed that they could give their genomic data for use by research without consent. It was considered that genomic data are just a kind of register or health information, which has been collected otherwise too, or it was thought that the benefits to research are great and the disadvantages to oneself small or non-existent. Some also thought that people do not have enough information to be able to make decisions, and this could be an obstacle to the benefits gained. It was also argued that the statutory collection and storage of genomic data could increase equality in healthcare because then "unmotivated" people could not counter the new opportunities brought by genomic data. Most positive views on the statutory use of genomic data were received from the groups of nurses, teachers and recovering addicts.

> "R4M1: Yes in my opinion the permission of the person who gave it should always be asked.
>
> R4N1: If there was some information about me, then it really wouldn't be necessary to ask me.
>
> Moderator: It wouldn't be necessary to ask you?
>
> R4N1: Yes. Let them do their studies. I don't see any terrible threats in it, however, that would affect my life in any way."

> "R5M1: Yeah I might go with the register principle., However, how well is it that an individual is able to understand the risks and possibilities of such a case. And then if you take the benefits from the other end that could come of it. So, hmm, I don't believe that an individual necessarily is able to decide about it."

Young people hoped more often that consent be asked, whereas older participants thought that permission would not necessarily have to be sought. The importance of consent was emphasised in the uses allowed for the data — not so much in which situations they are collected. If information exists, it should also be used for the benefit of individuals or in general for research and people. In fact, the consent model designed in line with the handling principle does not correspond to ordinary people's view of how and for what purpose permission should be sought.

7 CONCLUSIONS

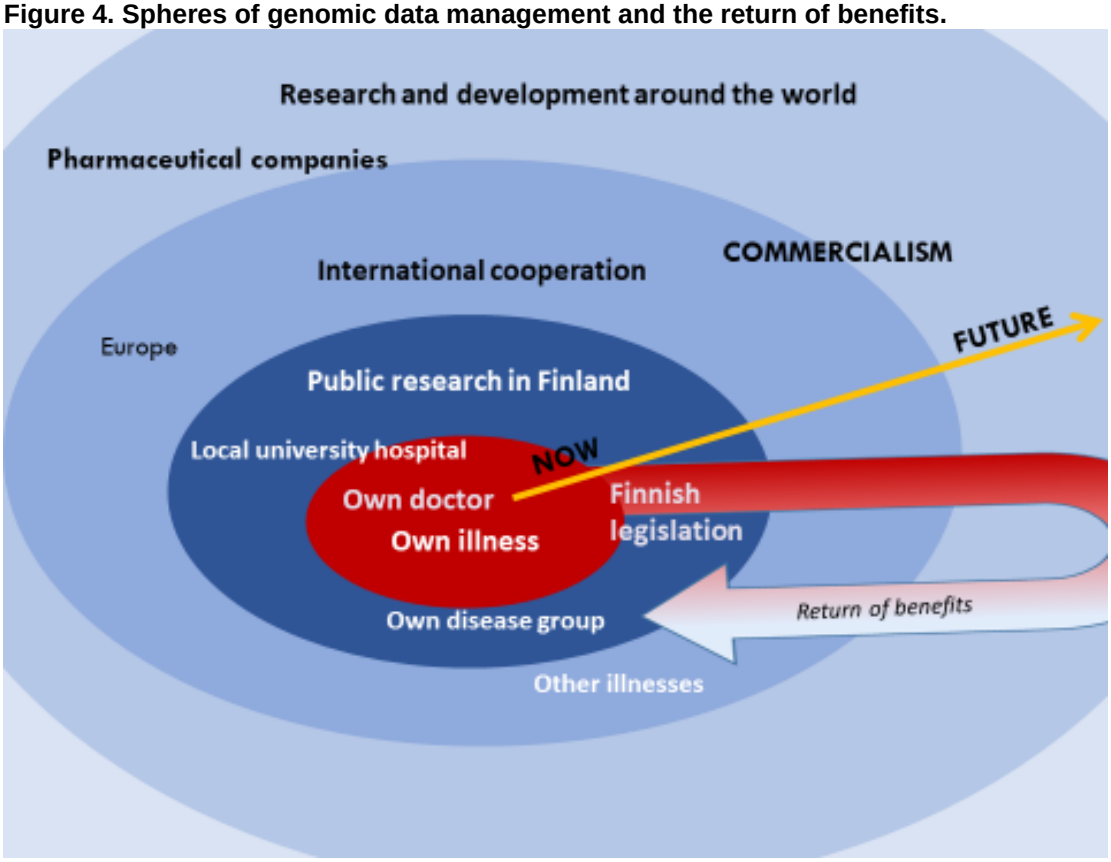
The concept of genome was largely unknown to most group members. For communications, it is good to be aware that the concept of genome, in particular, seemed troublesome. When the concept is unfamiliar, merely using it in a sentence is difficult even if the speaker would understand much about heredity and genetics. However, the participants talked fluently about genes and heredity. In fact, many of them said that they had joined the group because they themselves or their close family members had hereditary, or possibly hereditary, illnesses. For communications, it is important to note that it is harder to reach people who do not have a personal interest in understanding hereditary diseases.

As a rule, most participants felt that genomics research and the utilisation of the genome in research and healthcare was good. It was thought that this can help to achieve better health and the common good. However, the discussions do not support the view that Finns would want to give their data altruistically for utilisation. Motives for supporting genomics research were linked, in particular, with people's own experiences of hereditary diseases. It is then hoped that genomics research would help — if not the participants personally — at least others in the same situation. People set many conditions and restrictions for the use and collection of genomic data. Similar results have been obtained when studying people's concepts and expectations with respect to biobanks (Snell & Tupasela 2012, Tarkkala 2012). However, in addition to the common good, people also wish to have personal benefit from genomic data. Especially among younger group members, the reception of one's own data and their possible own use were often seen as a prerequisite for donating the data. People want to take part and pull their weight, but rather than altruism, we could talk about solidarity (Prainsack & Buyx 2017). The desire to help is linked with many personal wishes and, in particular, expectations of reciprocity and compliance with the welfare state's operating principles.

Often the discussions underlined the importance of planning the Genome Centre and projects associated with genomic data so that they would primarily support people's health and wellbeing. If this helps to increase employment or competitiveness in Finland, that was considered to be a good by-product. However, most group members expressed their concern that genomic data would be used for commercial purposes and that someone would do business with the data. Commercialism has been found to be one of the biggest concerns of people in regard to the use of health data, biomedicine and genomic data both in Finland and internationally (Caulfield et al. 2017, Snell et al. 2012, Critchley et al. 2015). Business activity is connected with the pursuit of economic advantages, increased inequality, lack of transparency and a greater risk of unethical operations. The return of benefits from commercial activities

to oneself and to Finnish health care or public health is considered especially problematic. Figure 4 illustrates how people perceive the use of their biological samples and health data. The further from your own circle of experience (e.g. your own doctor, your own illness or your own hospital) the use of data and samples goes (both in time and place), the more risks are associated with it. At the same time, there is less belief in returning benefits.

Figure 4. Spheres of genomic data management and the return of benefits.



The utilisation of genomic data was seen especially as a matter for the future. To be committed at present to the storage and use of genomic data in the future required strong confidence in the bodies administering the genomic data and in their ability to guarantee the return of benefits. The system to which people will be committed for decades must stand on a sustainable footing and its operations must be morally and ethically acceptable. In general, people trust in Finnish and public regulation and activities. Apart from commercial activities, the international operating environment poses challenges to trust as Finns do not have the same confidence in the regulatory and management mechanisms of other countries. Combining genomic data with other health, wellbeing or registration data poses an additional challenge. It was very

difficult for the participants to comprehend what information can be combined and used in research and product development and how this is done. Discussion on this topic was very scanty in the groups because the topic clearly seemed difficult to approach. This is significant, especially in terms of communications.

As a rule, the group members thus had a positive attitude to the collection, storing and use of genomic data, both in research and in healthcare. The most critical views often came from persons who in the past had had negative experiences of healthcare, healthcare information systems or the services provided by society on the whole. Negative experiences also have a strong impact on the acceptability of new operating policies and systems. Several studies have shown that, in a European comparison, Finns have a strong trust in various societal actors, in research and, for example, in public healthcare. This trust is based on the existing system and its history. Now that the whole healthcare system is being reorganised, it is not self-evident that the trust will transfer to the new system, of which people have no experience. This also affects the establishment of the Genome Centre.

The group discussions raised concerns about overly rapid changes and the rush to gain access to Finnish genetic heritage. The view was that it is disadvantageous to start implementing the use of genomic data on a broad front if the healthcare system and society are unable to bear the responsibility for the equal and health-promoting use of the data. It was thought that unnecessary rush can increase the potential exploitation of people and can produce information giving rise to measures that the individual or the healthcare system cannot respond to.

Most group members hoped that they would be asked for their consent to the storage and use of genomic data. It was difficult to distinguish between consent for storage and consent for use, because the group members themselves immediately linked storage with the opportunity to use the data. For consent, it was more important for which uses the data may be used than in which situations they have been collected. If information exists, it should also be used for the benefit of individuals or in general for research and people. In fact, the consent model designed in line with the legal basis of processing data does not correspond with ordinary people's view of how and for what purpose permission should be sought. Young people hoped more often that consent be asked, whereas older participants thought that permission would not necessarily have to be sought. A similar trend was also visible in the questionnaire survey on biobanks and consent (Snell 2017). Moreover, young people were the most eager to embrace the idea of dynamic consent and to receive data on themselves for their own use. Young people were also more likely to think that obtaining their genomic data for themselves is a prerequisite for the storage and use of the data. However, not only young people hoped that their data would be available for useful

purposes. Nearly everyone wanted to know more about their own genome and would gladly receive genomic data.

There is an urgent need for communications concerning the Genome Centre. The participants hoped that a wide variety of information would be distributed to people before the Genome Centre is established and before any data are stored in the Genome Centre. A few groups referred to biobanks and the communications about them. It was felt that information about biobanks has been received after the fact, and it has not always been ensured that messages actually reach people.

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