



UNIVERSITEIT VAN AMSTERDAM

**ESTONIA OUTCOMES SUMMARIES
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SUMMARY OF THE REPORT

In 2021 and 2022, tens of interviews were conducted in Estonia with experts in big data, AI, and human genome research. This research was lead by dr. Roanne van Voorst, a future anthropologist at the University of Amsterdam, and principal investigator of the HEALTH-AI project funded by the European Commission (ERC) and the Amsterdam Centre for European Studies (ACES). She was assisted for the interviews in Estonian by drs. Maria Vous.

The aim of this study was to gain a comprehensive understanding of the greatest opportunities and challenges, according to industry insiders, for the ethical development of personalized medicine and the broader digitalization of healthcare. Estonia was chosen for this research due to its global reputation for high levels of digitalization in healthcare.

This report presents the key findings from the interviews. All interviews were transcribed verbatim, but participants' names and any other identifiable information were kept completely anonymous to ensure the analysis could be conducted without compromising anyone's privacy.

We wrote this report as a thank you to all the participants. Their insights and experiences have been immensely helpful in mapping out this topic effectively; the time they dedicated to our conversations has been invaluable to the research. They serve as the foundation for our ongoing follow-up study, which will take place over the next few years in six countries around the world, including Estonia. It is important to note that this research will no longer focus on the topic of personalized medicine, per se, but instead will focus on a different but related subject: how doctors in hospitals collaborate with algorithms. Any questions or comments can be sent to the principal investigator, Dr. van Voorst, at r.s.vanvoorst@uva.nl, or to the researcher responsible for the research in Estonia, Drs. Albina Abzalova: a.abzalova@uva.nl

QUESTION 1 WHAT ARE THE BENEFITS OF PERSONALIZED MEDICINE?

According to our interviewees, personalized medicine, in potential, offers far-reaching benefits for individuals and society as a whole. Participants in our research highlighted that personalized medicine can lead to happier, healthier, and more successful lives for individuals. By tailoring treatments and approaches to each person's unique genetic makeup, personalized medicine can optimize health outcomes. This extends beyond healthcare, with participants mentioning personalized approaches being beneficial in other areas such as personalized food and education.

The potential of personalized medicine to reduce healthcare costs was also emphasized. By predicting diseases and enabling individuals to take proactive measures for their health, participants believed that healthcare costs could be lowered. This is of particular importance in addressing the challenges posed by the global healthcare crisis, including an aging population and limited resources. Personalized medicine has the potential to transform healthcare, shifting towards a more human-focused approach where individuals receive personalized assistance rather than a one-size-fits-all approach.

The benefits of personalized medicine are closely tied to the role of genes. Participants recognized that genes serve as a reliable source of truth and are incredibly personal. Genetic information provides valuable insights into an individual's health risks and predispositions, enabling earlier detection and intervention. By predicting and preventing diseases, personalized medicine can not only improve health outcomes but also save costs associated with healthcare. Additionally, participants highlighted the importance of personalized medicine in promoting individual engagement in health. When individuals understand that their health is in their hands and that personalized medicine can support their well-being, they are motivated to take action and make positive lifestyle changes.

Furthermore, personalized medicine offers specific benefits in predicting and addressing certain conditions or target groups. Participants mentioned the use of gene tests to predict breast cancer and invite high-risk women to early screenings. Personalized medicine also has potential in predicting conditions like hypercholesterolemia, type II diabetes, and rare diseases. By leveraging pharmacogenetics in treatment approaches, personalized medicine can improve medication effectiveness and reduce adverse reactions. Additionally, personalized medicine enables comprehensive cancer testing, leading to early detection and more targeted treatments. Overall, personalized medicine holds immense potential for improving health outcomes, reducing healthcare costs, and empowering individuals to take control of their well-being.

In summary, when participants were talking about the (future) benefits of personalized medicine, they brought out:

- **Far-reaching benefits**
 - People are happier, healthier, and live more successful lives because of personalized medicine and personalized approach to humans in general (for example, personalized food, personalized education etc)
 - Healthcare costs go down because diseases can be predicted and people take care of their health
 - A potential way to solve the global healthcare crisis (aging population, not enough resources and medical workers)
 - Healthcare will change to be more human-focused - instead of treating everyone the same, people would get personalized help
- **Benefits that come from genes**
 - Genes are a reliable source of truth
 - Genes are as personal as can be
- **Benefits that come from the fact that personalized medicine is preventive/predictive medicine**
 - Possibility to discover diseases earlier and therefore maximize the chances of getting better
 - Possibility to discover earlier and thus increase the number of healthily-lived years and lower the mortality rate
 - Predicting and preventing diseases and thus saving costs that go for healthcare
- **Benefits regarding getting people to take interest in their health**
 - People understand that their health is in their hands and thus are motivated to do something to keep healthy / improve their health
- **Benefits of being able to predict specific conditions or to help specific target groups**
 - Using gene tests to predict breast cancer and inviting women with high risk to screening earlier
 - Possibility to predict Hypercholesterolemia
 - Possibility to predict life-style diseases such as II type diabetes
 - Possibility to use pharmacogenetics in the treatment
 - Possibility to do more cancer testing
 - Possibility to discover and treat rare diseases

QUESTION 2 HOW DOES THE SELECTION PROCESS IN PERSONALIZED MEDICINE PRACTICE WORK?

During discussions regarding how diseases to be prevented or predicted through personalized medicine are chosen, participants shared the following insights:

In Estonia, the decision of which personal medical services are funded is made by the National Health Insurance fund. Various entities, such as professional societies, private companies, or other parties that meet the necessary requirements, can propose services for funding consideration. However, the likelihood of a new and innovative service being funded is low, as the requirements for evidence-based and clinically proven interventions are stringent. Cost-benefit analysis and other criteria are taken into account, often resulting in the prioritization of diseases with a strong genetic component that can bring significant value without being heavily influenced by behavioral factors. It was noted that the state's capability to provide services and the available budget play a significant role in determining the chosen services. Consequently, rare diseases and conditions tend to be overlooked due to their limited prevalence and potential cost implications.

In research institutions, the choice of diseases to study is influenced by grants and the personal interests of researchers. Researchers may select disease areas based on their expertise and passion for a particular field.

Private companies' choices of services and disease focus often depend on their profile and objectives. Factors such as market potential and profitability are considered, as companies need to sustain their operations. The influence of investors can play a role in shaping the company's priorities. Clinical studies and the presence of scientific evidence are also key considerations for private companies, ensuring that their services are grounded in sound research.

Overall, the selection of diseases for personalized medicine interventions involves a combination of factors, including evidence-based approaches, funding availability, market potential, investor influence, and the interests and expertise of researchers. These considerations shape which diseases receive attention and resources in the realm of personalized medicine.

In summary, when talking about how are the diseases that personalized medicine tries to prevent/predict chosen, participants said that:

- **In Estonia, the choice of which personal medical services get funded is made by the National Health Insurance fund**
 - Services can be proposed by professional societies, private companies, or other parties who have met all the necessary requirements
 - As everything needs to be evidence-based on clinically proven, chances of getting something very new funded are low
 - The choice is made based on cost-benefit analysis amongst other criteria, meaning that rare diseases and conditions usually don't get chosen

- At the moment, diseases with the strong genetic component are favored as they bring the most value and are not dependent on the behavioral component so much
- State's capability to provide services and budget play a big role in choosing the services
- **In research institutions, the choice of which diseases to study depends on grants and researchers' own personal interest**
- **In private companies, the choice of service / which disease to focus on depends on the company's profile**
 - It can be based on market potential and profitability
 - It can be affected by investors to various degrees
 - Clinical studies and scientific proof play a key role

QUESTION 3 WHAT WILL THE FUTURE LOOK LIKE,

IF PERSONALIZED MEDICINE HAS BECOME MORE WIDESPREAD?

When discussing the future patient and the future of healthcare, participants expressed a range of opinions, including:

Healthcare is expected to shift from a focus on treatment and diagnosis towards prevention and prediction. The extent of this change will depend on the utilization of genetic technology and personalized medicine. Participants likened personalized medicine to a tool, similar to the internet, and acknowledged that it is not a cure-all solution and cannot prevent every disease.

There was a belief that people will become more aware of and take greater responsibility for their own health. The expectation is that individuals will take proactive measures to prevent diseases and maintain their well-being. It was also mentioned that people are living longer lives without diseases, suggesting a shift towards healthier aging.

The concept of health and illness was considered relative, with the understanding that everyone will have some form of disease or health condition. Feeling healthy was seen as being influenced by one's mindset. In this context, individuals with good analytical skills and a sufficient understanding of the field would benefit more from personalized medicine.

Participants generally agreed that people should take more responsibility for their health. This includes greater involvement in disease prevention, taking control of health-related processes, and making conscious decisions about their well-being. People were seen as learning from their own experiences, making changes in behavior, and seeing positive results. It was emphasized that understanding the importance of prevention is crucial, going beyond mere appearance and incorporating a focus on overall health.

However, while individuals were encouraged to take responsibility for their health, participants acknowledged the need for support. Consultation with healthcare professionals was seen as important in helping patients understand their specific risk scores and empowering them to take appropriate action. Participants expressed a desire for a centralized and trustworthy source of information, similar to a patient portal, where individuals could access relevant health-related information. The importance of early education and understanding of such services and responsibilities was stressed, starting from kindergarten, school, and within the family. Participants recognized that while health is an individual responsibility, people still require advice and support.

Overall, participants saw a future where individuals are more involved and responsible for their health, supported by access to information, consultations, and education. The potential of personalized medicine was seen as an empowering tool to help people make informed decisions and take control of their well-being.

In summary, when asked about the future patient and the future of healthcare, participants had many, varying opinions:

- **Healthcare will change from treating and diagnosing to prevention and prediction**
- **The changes depend on whether we use the possibilities genetic technology and personalized medicine offer and to what extent**
 - Personalized medicine is a tool like the Internet
 - Personalized medicine isn't all-powerful and won't allow us to prevent everything
- **People are more aware and take more responsibility for their health**
- **People are living longer without diseases**
- **Concepts of healthy and sick are relative**
 - Everyone will have some disease, there are no such things as 100% healthy
 - Feeling healthy is a lot about mindset
- **People with good analytical skills and who can understand the field enough to make conscious decisions will win from personalized medicine**

In general, participants saw that people should / would be able to take more **responsibility for their health**, but also that people probably need some support:

- **People should take responsibility for their health**
 - People should be more involved in trying to prevent diseases
 - People should take more control over initiating health related processes themselves
 - People will learn by experience - find out something about themselves, change behaviour, see result
 - People understand why they need to do some things - it's not just about losing weight and looks, but about prevention
 - People are empowered by personalised medicine to take more responsibility about their health

- **Support is necessary**

- Consultation plays a crucial role in helping patients to understand that specific risk scores mean and about what they can do about it
- There should be one and safe place for all informations (à la Patient portal) so people would know where to turn
- The education and understanding how to deal with these new services and about their responsibility about their health has to start early - kindergarten, school, family
- Although health is an individual responsibility, people also need to get advised and get support

QUESTION 4 WHAT ARE POTENTIAL CHALLENGES WHEN IT COMES TO (ETHICAL) DEVELOPMENT OF PERSONALIZED MEDICINE?

Participants acknowledged that effectively communicating the value of personalized medicine to the general population could be challenging. They highlighted several factors that contribute to this difficulty. Firstly, participants recognized that the result of a gene test is often a probability or a numerical value. Communicating the significance and necessity of personalized medicine services in a way that resonates with individuals and encourages them to take action is a complex task. Strategies for effectively conveying this information will be crucial in encouraging uptake.

Another challenge lies in the potential disparity between people's expectations and the reality of what personalized medicine can currently offer. Participants emphasized that individuals may have a misguided understanding of what is possible and what is not. This can lead to unrealistic or exaggerated expectations, which, if not met, may result in disappointment and a lack of trust in personalized medicine. Clear and realistic communication about the capabilities and limitations of personalized medicine will therefore be essential in managing these expectations and building trust among the general population.

Lastly, participants noted that gene testing and personalized medicine concepts are unfamiliar to most lay-people (non-medically trained, not having a background in statistics or big data). The need for education and consulting services in order to increase awareness and understanding of personalized medicine was emphasized. Establishing comprehensive educational initiatives that explain the benefits, processes, and potential risks associated with personalized medicine will be crucial in overcoming this unfamiliarity. By providing accessible information and guidance to the general population, personalized medicine can become more widely accepted and embraced.

Overall, while participants recognized the clear benefits of personalized medicine, they also acknowledged the challenges in communicating its value to the general population. Addressing these challenges will require effective communication strategies, managing expectations, and providing education and consulting services to increase awareness and understanding. By addressing these barriers, personalized medicine can be better understood and embraced by individuals, leading to improved health outcomes for all.

In summary: although the benefits were clear to them, participants brought out that making the value of personalized medicine clear for the general population is going to be more difficult:

- The result of a gene test is a probability, a number – **how to communicate the value and the need for personalized medicine services so people would take it up**
- People might have a very misguided understanding of what's possible and what's not – **expectations and reality might not match or might be disappointing**
- Gene testing and personalized medicine topics are unfamiliar to most people – **the need for education and consulting**

Participants highlighted numerous other challenges that personalized medicine is currently facing. These challenges pertain to various aspects of the field, ranging from project implementation to data management, collaborations, communication, and the overall usefulness of personalized medicine.

Regarding the Estonian personalized medicine project, participants pointed out several difficulties. These include multiple parallel processes and parties involved, as well as the project being conducted primarily as ongoing research to gather proof of concept. Additionally, a lack of political vision and complexity in the IT infrastructure pose challenges. Establishing a robust legal framework is also necessary to support the implementation and sustainability of personalized medicine initiatives.

Data-related challenges were also highlighted by participants. These include potential lack of trust from individuals in providing their data or opting out of being informed about their health risks. Additionally, issues with data quantity, quality, diversity, access, sharing, and compliance with (over)regulation further complicate the utilization of personalized medicine data.

Collaboration challenges were mentioned, particularly in terms of forging partnerships between the state and private companies. Training healthcare workers and assigning them additional responsibilities in personalized medicine implementation was also identified as a challenge. Coordination and alignment of efforts between different stakeholders will be crucial to effectively integrate personalized medicine into the healthcare system.

Participants also acknowledged challenges concerning how individuals react to personalized medicine results. Effective communication about personalized medicine, especially risk scores, is important to prevent anxiety or stress and ensure that they are understood correctly. Promoting behavioral change to improve health outcomes is recognized as a complex and long-term process that requires careful consideration and support.

Lastly, concerns about the usefulness and equity of personalized medicine were raised. Participants questioned whether it is wise to invest in personalized medicine if only a select few individuals benefit from it. Ensuring that personalized medicine services can be accessed and utilized by a wider population without creating further disparities is a challenge that needs to be addressed.

In summary, participants identified a range of challenges facing personalized medicine, including project implementation, data management, collaborations, communication, and the need for equitable access and usefulness. Overcoming these challenges will be vital in realizing the full potential of personalized medicine and ensuring its successful integration into healthcare systems.

In summary, in addition to difficulties regarding making the value clear, participants mentioned many **challenges that** personalized medicine is, or could still be facing the next years:

- **Challenges regarding Estonian personalized medicine project**
 - Many parties and processes run in parallel
 - Has been done as a research project where proof is gathered on an ongoing basis
 - Lack of political vision
 - The complexity of the IT part of it
 - Legal framework needs be built
- **Challenges regarding the data**
 - Potential lack of trust and people not giving their data or opting out of being informed about their risks
 - Problems around the amount and quality of data, diversity of data, access to data, sharing the data, and using data
 - Problems arising from the (over)regulation of the field
- **Challenges regarding collaborations**
 - Weak vision for collaboration between state and private companies
 - Training healthcare workers and adding extra responsibility and tasks for the general physicians
- **Challenges regarding how people react to the results**
 - How to best communicate what personalized medicine is?
 - Possibility of risk scores causing anxiety and stress instead of helping people to improve their health
 - People not understanding what the risk scores mean or misunderstand them
 - Behavioral change is a complex and long-term process
- **Challenges regarding the usefulness of personalized medicine**
 - Is it wise to invest in personalized medicine if only some people win from it?
 - How to build a personalized medicine service in a way that not only a few would benefit from it?

QUESTION 5 WHICH RISKS ARE INVOLVED, OR SHOULD BE CONSIDERED WHEN IT COMES TO THE DEVELOPMENT OF PERSONALIZED MEDICINE IN ESTONIA?

Participants recognized that many challenges also pose potential risks in the context of personalized medicine. These risks are multifaceted and extend to various areas, including the understanding and interpretation of risk scores by individuals, potential errors in the risk assessment process, financial implications, and data-related concerns.

One of the main risks highlighted by participants is the potential for people to misunderstand risk scores. This can lead to various negative consequences, such as heightened anxiety and stress among individuals who receive high-risk scores. Conversely, false hopes may arise when individuals receive low-risk scores and fail to take necessary precautions or interventions. Additionally, some participants expressed concerns that risk scores may create a sense of hopelessness, as individuals might perceive that their future health is predestined by these predictions.

Errors at any stage of the process of providing risk scores were also identified as a potential risk. These errors could include inaccuracies in data collection, analysis, or interpretation, which may result in incorrect risk assessments and subsequent actions or interventions.

Financial risks associated with personalized medicine were also highlighted. Pouring excessive resources into personalized medicine without considering alternative areas where the money might have a greater impact was seen as a potential risk. Additionally, the risk of overtreatment – providing unnecessary interventions or treatments based on risk scores – was identified as a concern.

Data-related risks were emphasized, particularly in regard to the predictive models used in personalized medicine. Overly predictive models may generate risk scores that are not truly indicative of an individual's actual risk, leading to inappropriate actions or interventions. Models that perform well on homogenous groups but fail when applied to diverse populations pose both ethical and practical risks. Data leaks and breaches also present risks to the privacy and security of sensitive personalized medicine data. Lastly, accurately evaluating the effectiveness and reliability of personalized medicine systems and approaches was recognized as a challenging task.

In summary, participants highlighted various risks associated with personalized medicine, including the potential for misunderstanding of risk scores, errors in the risk assessment process, financial implications, and data-related concerns. By acknowledging and addressing these risks, personalized medicine can strive for improved accuracy, ethical implementation, appropriate resource allocation, and enhanced data security, while mitigating potential negative impacts on individuals and healthcare systems.

In summary: many of the things that were mentioned as challenges, were also seen as potential risks by participants:

- **Risks related to people misunderstanding the risks scores**
 - People getting anxious and stressed
 - False hopes
 - Feeling of hopelessness, like everything's predicted
- **Risks related to making mistakes** anywhere along the process of providing a risk score
- **Risks related to money**
 - Pouring money into personalized medicine when the money might be more useful somewhere else
 - Overtreatment
- **Risks related to data**
 - Over-predictive models
 - Models working well on homogenous groups
 - Data leaks
 - Evaluating of how well a certain system works might be difficult

QUESTION 6 WHAT IS THE ROLE AND VALUE OF BIG DATA WHEN IT COMES TO PERSONALIZED MEDICINE?

The participants in the discussion recognized the immense value of data.

They likened data to gold and referred to Estonia as a potential gold mine of data. This suggests that they viewed data as a highly valuable and potentially lucrative resource.

Participants expressed a belief that computers analyzing data are more reliable than humans making decisions. They highlighted that computers make fewer mistakes compared to humans and, in some cases, no mistakes at all. They also expressed a concern that human error poses a greater risk to data security than computer systems.

There was an understanding that the more data available, the more value can be derived from it. Participants mentioned various sources of data that could contribute to extracting greater value, such as sequencing passports when individuals are born, analyzing data collected over longer periods of time, utilizing secondary data sources, combining behavioral data (such as exercise and nutrition) with genetic data, and having access to data from different health-related databases. They emphasized that innovation in healthcare lies in the utilization of more data.

Overall, participants recognized the significant value of data in healthcare. They regarded it as a precious resource that, when properly utilized, has the potential to bring about transformative advancements in healthcare and improve decision-making processes.

In summary, data was seen as very valuable by most of participants:

- **Data is gold and Estonia has a potential gold mine of data**
- **Computer performing on data are more reliable than people making decisions**
 - Computers make less mistakes than people
 - Computers don't do mistakes at all
 - The weakest link of data security is human, not a computer
- **The more data there is, the more value it's possible to get out of it**
 - Sequencing passports when a person is born
 - Data across from longer period of time
 - Secondary data
 - Data about people's behavioral aspects (exercise, nutrition etc) combined with genetic data
 - Access to data in different health-related data-bases
 - Innovation lies in more data

QUESTION 7 WHAT SHOULD BE A PATIENT'S RIGHTS REGARDING THEIR DATA?

When discussing a person's rights regarding their data, participants raised several important thoughts and questions, reflecting the complex ethical and legal considerations surrounding data privacy and ownership in the context of personalized medicine.

Participants emphasized the importance of individuals having the right to choose whether they want to know about their health risks or opt-out of certain services. Respecting individuals' autonomy in deciding what information they want to receive is crucial in personalized medicine.

The question arises as to whether it is necessary or even beneficial to inform individuals about risks for which there may be no actionable interventions. Some participants questioned whether it is valuable to burden individuals with information that they cannot do anything about, considering the potential psychological and emotional impact it may have.

The issue of consent and control over personal data was also raised. Participants pondered whether individuals should have the right to delete their data or withhold consent for its use, even if that data could contribute to the creation of services that benefit the broader population. Determining the extent to which individuals truly own their data and the rights and responsibilities that come with it is a complex and evolving topic in the era of personalized medicine.

Transparency and accountability were highlighted as essential principles in data management. Participants emphasized the need for individuals to have the ability to inquire about who has accessed their data, what has been done with it, and who has utilized it. Individuals should have a say in how their data is utilized and the power to make decisions regarding its handling.

The frequency and manner in which individuals are asked for consent to use their data was deemed an important consideration. Establishing appropriate protocols for obtaining informed consent requires careful thought, balancing the need for individuals to be aware and involved with the practicalities of delivering efficient and effective healthcare services.

Participants recognized the sensitivity of genetic data and the heightened concerns individuals may have regarding its privacy and security.

It was noted that many individuals have low levels of knowledge about data protection, indicating a need for improved education and awareness surrounding data privacy and rights.

The potential for individuals to benefit from their data was discussed, including the possibility of selling or exchanging it for services that provide personal value. This highlights the potential for data to become a valuable commodity and raises questions about the ethical implications and potential impacts on privacy and equity.

Lastly, participants noted that in the Estonian context, individuals generally have a good understanding of how genetic data is used in healthcare services and display a relatively low level of concern regarding the use of their data.

In summary, participants raised important thoughts and questions about an individual's rights regarding their data in the context of personalized medicine. These considerations revolve around informed consent, data ownership, transparency, accountability, education, privacy, and the potential for individuals to benefit from their own data. Addressing these questions and finding appropriate solutions is crucial to ensure that personalized medicine respects individuals' rights and maintains public trust.

When talking about a **person's rights regarding their data**, participants specifically brought out the following thoughts and questions:

- People should have the right not to know about their risks, to opt-out or at least close services they don't want to use
- Should we really tell people about things they can't do anything about?
- Should people be allowed to delete the data or not give consent to use data if this data could be used for creating services that benefit everyone?
- Who owns the data? Is it always a person's possession and to what extent?
- People should be able to ask the State who has seen their data, what has been done to their data, who has used the data, and decide themselves what to do with their data
- When and how and how often should people be asked for consent to use their data?
- Genetic data is sensitive so people might have heightened concerns about it
- People's data protection knowledge is generally low
- People might as well benefit from their data - for example, sell it or give it for services that bring them value
- Estonians don't worry a lot about their data when it comes to healthcare services and have a pretty good understanding of how genetic data is used

QUESTION 8 HOW DO ESTONIANS PERCEIVE PERSONALIZED MEDICINE? ARE THEY ENTHUSIASTIC ABOUT IT, OR SCARED BY IT?

According to participants, the general population's perception of personalized medicine can vary, but several key insights were highlighted during discussions:

Fear was identified as a potential motivating factor for people to participate in personalized medicine initiatives. The prospect of uncovering untreatable diseases or the question of whether individuals want to know about their own mortality were mentioned as factors that might drive participation. However, it was also noted that some individuals may have apprehensions due to the unfamiliarity of gene technology and the potential implications of genetic information.

The overall acceptance of gene technology was reported to be quite good. Participants noted that the majority of individuals who have donated their genes to Geenivaramu (a genetic database in Estonia) have not opted out of knowing about their health risks. People expressed eagerness to see how their data is being used, suggesting a trust in science and researchers. It was also acknowledged that over the past two decades, efforts have been made to educate the public about gene technology, resulting in the integration of the term "gene" into everyday language in Estonia.

General physicians were described as open to the use of personalized medicine as long as it is based on clinical studies and scientific evidence. This indicates that healthcare professionals are receptive to incorporating personalized medicine approaches into their practice, provided there is a solid foundation of research and data supporting their effectiveness.

However, participants highlighted the lack of scientific studies examining how people perceive or feel about personalized medicine and related topics. This represents a gap in current knowledge and suggests a need for research to better understand public attitudes and beliefs.

The role of service design was emphasized as crucial for the acceptance of personalized medicine services. Creating user-friendly and accessible services that meet the needs and expectations of individuals is seen as essential for their acceptance and utilization.

Hence, participants provided insights into how the general population perceives personalized medicine. The potential impact of fear, the overall acceptance of gene technology in Estonia, the openness of general physicians, the lack of scientific studies on public perceptions, and the importance of service design were key themes that emerged from the discussions. Understanding the attitudes and concerns of the general population is vital for the successful implementation and acceptance of personalized medicine initiatives.

In summary, when asked about how the general population sees personalized medicine, participants said that:

- **Fear might encourage participation**
 - People have not always coped well with knowing about untreatable diseases
 - “Do I want to know when I die?”
 - The topic of gene technology is unfamiliar to many people
- **The general acceptance of gene technology is very good**
 - Only a few of the people who donated their genes to Geenivaramu have opted out of knowing about their risks and most people are eager to see how the data is used
 - A lot of work has been done over the last 20 years to educate people about this topic – “gene” has become a normal, everyday word
 - People trust science and researchers in Estonia even if they don’t trust the government
- **General physicians are open to using personalized medicine as long as it’s based on clinical studies and science**
- **There are no scientific studies done about how people perceive or feel about personalized medicine and topics related to it**
- **Service design plays a crucial role in whether personalized medicine services will be accepted or not**

QUESTION 9 SHOULD MEDICAL EXPERTS, AND THE CLINICS THEY WORK FOR, COLLABORATE WITH PRIVATE COMPANIES IN OFFERING PERSONALIZED MEDICINE IN ESTONIA?

Participants had mixed opinions about collaboration with private companies in offering personalized medicine services:

Regarding pharmaceutical companies, participants expressed a neutral stance. While there was potential interest in collaboration, the involvement of pharmaceutical companies in personalized medicine services was still vague and unclear. Participants recognized that as the state does not produce drugs, someone (such as pharmaceutical companies) has to handle this aspect. The effectiveness of drugs was viewed as more important than how the companies may have obtained access to data through potentially questionable methods.

Private companies, on the other hand, were generally seen as a nuisance. It was highlighted that direct consumer gene testing is not regulated, leading to concerns about the reliability and consistency of the results. Each company uses its own models, making it difficult to compare scores across different platforms. Patients often undergo commercial gene tests and bring the results back to their doctors, who may be uncertain about how to interpret or utilize this data. This mismatch between patient expectations and professional understanding can lead to frustration, particularly when patients perceive themselves to be at high risk without clear guidance on how to proceed.

Participants emphasized that private companies need to be certified and trustworthy in order for collaboration to be effective.

Interestingly, private companies themselves expressed a desire to be involved but felt intentionally left out. This suggests that there may be a disconnect or lack of communication between private companies and other stakeholders within the personalized medicine field.

Overall, participants had varying views on collaboration with private companies in offering personalized medicine services. While pharmaceutical companies were viewed neutrally and potentially seen as necessary partners, private companies were seen as problematic due to regulatory concerns and inconsistent practices. Building trust and certification were considered essential for collaboration to work effectively.

In summary, participants' thoughts on **collaboration with private companies** in offering personalised medicine services were mixed:

- **Pharmaceutical companies are seen neutrally**
 - Pharmaceutical companies could potentially be interested in collaboration, but the haven't been involved so far so the topic is still quite vague
 - As the state isn't producing drugs, someone (companies) have to
 - If the drugs work then the fact that the company might have gotten access to data using shadowy methods might not be that relevant
- **Private companies are rather seen as nuisance**
 - Direct consumer gene testing is not regulated
 - Each company uses their own models so the scores are not universal
 - Patients go and do commercial gene tests and take this data back to their doctor who doesn't know what to do with it, but patients are agitated because of "high risk"
 - Private companies need to be trustworthy = certified, for collaboration to work
- **Private companies themselves would like to be involved, but feel intentionally left out**

QUESTION 10 WHO IS RESPONSIBLE FOR MISTAKES WITH THE DEVELOPMENT OF, OR PRACTICE OF, PERSONALIZED MEDICINE?

Participants had differing opinions on who should be held responsible in case of mistakes, particularly in calculating risk scores. The following points were raised:

Participants believed that the producer of the medical device should be held responsible for any mistakes made. They held the view that the responsibility for accuracy and reliability lies with the company that produces the device or software used in calculating risk scores.

They emphasized that responsibility is typically defined in contracts. In the case of private companies whose models have been certified as medical devices, they would be responsible for the end user, while their collaboration partners would be responsible for other aspects of the process.

Participants made it clear that the computer itself cannot be held responsible for mistakes. They reasoned that any errors must have occurred somewhere in the process by a person. This suggests that the responsibility lies with individuals involved in using the medical device or software.

It is important to note that there was some confusion among participants about the exact distribution of responsibility. In certain situations, physicians would attribute responsibility to technicians, and vice versa, in terms of keeping track of evaluations and monitoring.

Overall, participants expressed different viewpoints on the responsibility for mistakes in calculating risk scores. While there was a consensus that the producer of the medical device holds responsibility, there seemed to be some ambiguity and differing perspectives regarding the division of responsibility among individuals involved in the process.

When it came to **mistakes and who is responsible when a mistake is made** in calculating risk score for example, participants said that:

- **The producer of the medical device is responsible**
- **Responsibility is defined in contracts**
 - In case of private companies (whose models have been certified as medical devices), they would be responsible for the end user and their collaboration partners would be responsible for other things
- **The computer is not responsible**
 - The mistake had to be done somewhere along the process by person

NB: there was also confusion about who, exactly, carried the responsibility. Sometimes, physicians would point to technicians, and vice versa, for keeping track of the evaluations and monitoring.



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THIS RESEARCH WAS LEAD BY

dr. Roanne van Voorst, a future anthropologist at the University of Amsterdam,
and principal investigator of the HEALTH-AI project,
funded by the European Commission (ERC)
and the Amsterdam Centre for European Studies (ACES).
She was assisted for the interviews in Estonian by drs. Maria Vous.

Any questions or comments can be sent to the principal investigator,
Dr. van Voorst, at r.s.vanvoorst@uva.nl,
or to the researcher responsible for the research in Estonia,
Drs. Albina Abzalova: a.abzalova@uva.nl

We wrote this report as a thank you to all the participants.
Their insights and experiences have been immensely helpful in mapping out this topic effectively;
the time they dedicated to our conversations has been invaluable to the research.
They serve as the foundation for our ongoing follow-up study, which will take place over the next few
years in six countries around the world, including Estonia.

It is important to note that this research will no longer focus on the topic of personalized medicine,
per se, but instead will focus on a different but related subject: how doctors in hospitals collaborate
with algorithms.