



# Genome strategy

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# Introduction

The development of research methods has led to a rapid increase in the amount of genetic information available as extensive genetic studies have become possible in both scientific research and clinical work. Genetic information produced in clinical work is currently used in the diagnostics, treatment selection, monitoring and prevention of several diseases. In scientific research, extensive data sets and combining genetic data with other health data enables the making of new observations and utilising these observations in promoting health and welfare.

In recent years, systematic collection of genomic information has increased in several countries, as the possibilities of medicine utilising genomic information have been recognised globally. Many countries have drawn up strategies and action plans related to the wider use of genomic data. Opportunities and needs related to the use of large genetic data sets have been considered and identified, and extensive projects that pilot the use of genomic data and aim to utilise genomic data have been launched. The table below presents examples of Finnish and international projects related to the use of genetic information:

Abbreviation	Project name	Short description of the project	Link
<b>FinnGen</b>	<b>FinnGen</b>	Genomic data obtained from the genome are combined with data in national health care registers to increase understanding of the causes of illnesses and to promote their diagnosis, prevention and treatment development.	<a href="https://finngen.fi/en">finngen.fi/en</a>
<b>P5</b>	<b>P5 study</b>	Participants in the P5 study will receive information related to their genetic risk of developing key noncommunicable chronic diseases.	<a href="https://thl.fi/en/web/thlfi-en/research-and-development/research-and-projects/the-p5.fi-study-genetic-information-for-health-support">thl.fi/en/web/thlfi-en/research-and-development/research-and-projects/the-p5.fi-study-genetic-information-for-health-support</a>
<b>GeneRISK</b>	<b>GeneRISK</b>	The study will examine whether common Finnish noncommunicable chronic diseases (especially cardiovascular diseases) can be prevented by utilising genomic information. The study will examine how receiving genomic data and risk assessments based on it affects people's health behaviour and thus the prevention of diseases. The project will test the KardioKompassi application for sharing information to participants	<a href="https://generisk.fi/kardiokompassi.fi/">generisk.fi/kardiokompassi.fi/</a>
<b>INTERVENE</b>	<b>INTERVENE</b>	The aim of the project is to develop and utilise new kinds of tools that are based on genomic data and suitable for assessing the risk of falling ill. The goal is to demonstrate the benefits of using artificial intelligence in the preparation of disease risk assessments based on genomic data and to test the utilisation of risk information in practical patient work.	<a href="https://interveneproject.eu/">interveneproject.eu/</a>

<b>SISu</b>	<b>Sequencing Initiative Suomi</b>	Collecting Finnish genomic data in the SISu data repository so that genomic information can best be available for use by Finnish doctors and researchers.	<a href="http://sisuproject.fi/">sisuproject.fi/</a>
<b>Profitu</b>	<b>Profitu</b>	Developing the competence of health care personnel in utilising genetic information by integrating genetic information into the education of health care personnel and developing qualifications so that they meet the challenges of working life and society.	<a href="https://projects.tuni.fi/profitu/in-english/">https://projects.tuni.fi/profitu/in-english/</a>
<b>1+MG</b>	<b>1+ Million Genomes Initiative</b>	A Europe-wide declaration of cooperation in which member states collaborate to create opportunities for secure cross-border use of genomic data for the benefit of citizens, ensuring the protection of privacy.	<a href="http://digital-strategy.ec.europa.eu/en/policies/1-million-genomes">digital-strategy.ec.europa.eu/en/policies/1-million-genomes</a>
<b>B1MG</b>	<b>Beyond 1 Million Genomes</b>	Supporting the implementation of the 1+MG Declaration of Cooperation by accelerating the development of European infrastructure.	<a href="http://b1mg-project.eu/">b1mg-project.eu/</a>

The Health Sector Growth Strategy for Research and Innovation Activities published in 2014 included a proposal for a national report on the national level preparation required by the increasing use of genetic information. To this end, in September 2014, the Ministry of Social Affairs and Health appointed a working group to draft a national genome strategy, *'Improving health through the use of genomic data'*, which was published in May 2015. The key proposals contained in the report were the enactment of the Genome Act and the establishment of a national Genome Centre. After the publication of the Genome strategy (2015), the preparation of the Genome Act and the Genome Centre continued under the guidance of the Ministry of Social Affairs and Health. When six years had passed since the publication of the strategy in spring 2021, it was considered necessary to examine various changes in the operating environment and their possible impacts on the content of the genome strategy. The Ministry of Social Affairs and Health issued a mandate to the Finnish Institute for Health and Welfare (THL) to convene a national high-level expert working group on genomic medicine. One of the key objectives of its term (1 March 2021 – 30 June 2022) was to update the genome strategy to correspond to current knowledge, understanding and needs.

The operating environment related to the utilisation of genome and health information is extensive, complex and constantly developing. Several international research projects are underway that focus on different themes of health information utilisation, including management models, quality and harmonisation, data sharing in cross-border environments and the role of citizens. The table below presents a few examples of such projects. In addition, there are a number of clinical projects that have been excluded from this listing.

Abbreviation	Consortium Name/ ecosystem	Short description of the project	Link
<b>EDHS</b>	The European Health Data Space	The European Health Data Space is a health ecosystem consisting of rules, common standards and practices, infrastructures and governance frameworks.	<a href="https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en">health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en</a>
<b>Nordic Commons</b>	Nordic Commons	The aim of the Nordic Commons project is to test solutions and practical approaches for sharing health information between regional and national operators in the Nordic countries.	<a href="https://nordforsk.org/nordic-commons">nordforsk.org/nordic-commons</a>
<b>GA4GH</b>	The Global Alliance for Genomics and Health	An organisation that frames policies and sets technical standards in order to enable responsible sharing of genomic data within a human rights framework	<a href="https://ga4gh.org/">ga4gh.org/</a>
<b>ICPerMed</b>	International Consortium for Personalised Medicine	IBrings together more than 30 European and international partners representing ministries, financial agencies and the European Commission. Together, they coordinate and promote research to develop and evaluate personalised medical approaches.	<a href="https://icpermed.eu/">icpermed.eu/</a>
<b>NHGRI Genomic Medicine Working Group</b>	NHGRI Genomic Medicine Working Group	The working group assists the American National Advisory Council for Human Genome Research in advising NHGRI on research needed to evaluate and move genomics into routine medical practice.	<a href="https://genome.gov/about-nhgri/National-Advisory-Council-for-Human-Genome-Research/Genomic-Medicine-Working-Group">genome.gov/about-nhgri/National-Advisory-Council-for-Human-Genome-Research/Genomic-Medicine-Working-Group</a>

During the process of updating the genome strategy, a number of issues and challenges were identified, which were not fully agreed on between the experts and to which finding solutions is not possible at this stage. In response to the sometimes rapid changes in the operating environment, experts emphasise the need for a solution-oriented and evolving genome strategy, which enables updating earlier policies and developing legislation related to genomic information when necessary.

## Vision:

Better health through the use of genomic information

## Mission:

Equal, broader, more efficient and ethically acceptable utilisation of genomic information as part of the Finnish health care system as well as the genomic sector service and export industries.

## Strategic goals:

- 1) Finland makes use of its unique prerequisites in research, development and innovation (RDI) in genomics
- 2) Knowledge of the current state lays the foundation for utilising genomic information in health care and promoting people's welfare
- 3) Solutions for the production and management of genomic information that take the development of the field into account will be produced.
- 4) Fluent utilisation of genomic information is possible in an ethically sustainable manner

## Strategy enablers:

Commitment, adequate resourcing, cooperation

## Strategy process

This strategy is an update of the genome strategy published in 2015. During the strategy process, the genome strategy has been discussed at the meetings of the expert group participating in updating it. The strategy draft was presented and discussed in autumn 2021 and in spring 2022 in four workshops, in which the strategy was discussed among the expert group and other invited experts.

# Strategic goal 1:

## Finland makes use of its unique prerequisites in research, development and innovation (RDI) in genomics

Over the decades, Finland has invested significant public funds in health-related research, which has helped us to become one of the leading countries in science (including genetic research). At the moment, however, Finland is lagging behind its reference countries regarding the level of investments in research and development (R&D): In the last decade, the development of the GDP share of Finland's R&D expenditure has been among the weakest in the EU Member States. The investment in research has not been fully utilised and the investments made have not sufficiently contributed to economic activity and added value. Our country's RDI activities can utilise the strengths which we are well known for: solid experience and know-how related to scientific research, high-quality national infrastructures (including the biobank network) as well as competence and readiness to develop and implement various new solutions enabled by digitalisation and technological development. In particular, pharmaceutical development and digital health care research could offer various business, growth and employment opportunities based on the utilisation of genetic information

### **MEASURE 1:**

#### **Creating and describing a service path that supports research activities**

Effective national and international RDI activities requires an efficient and straightforward channel for samples and information available for research purposes. Utilising the data requires knowledge of the regulations and the ability to find the most effective solution in each case. Based on ecosystem thinking and a customer-oriented concept, a service path is described for the promotion and smooth implementation of data-driven research, bringing together and making visible the services offered by different operators to companies and research organisations (including sample and data disclosure, research and contract matters and finding the right partners). A clear description of the service path and a smooth service will also promote Finland's attractiveness to international RDI activities.

### **MEASURE 2:**

#### **Developing operating models for public-private cooperation**

Operating models will be developed for cooperation between the public and private sectors, which will enable the smooth utilisation of genetic data and related health data in both domestic and international research and product development projects. The cooperation models created will speed up the resolution of the actual RDI challenge, as there is no need to consider and solve the operating model applied in each project separately. Existing cooperation models can be utilised and further refined. In addition to the utilisation of genetic data, extending the operating models developed to the utilisation of other health data is promoted.

**MEASURE 3:****Promoting the use of genomic information generated in Finland in RDI activities**

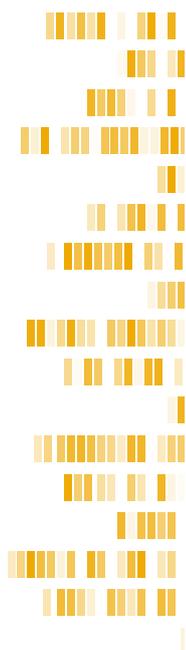
The quality assured genomic data generated in Finland will be widely distributed for secondary use in research and development so that it can be flexibly combined with the available health and well-being data. The preconditions for the measure are compliance with national and international ethical guidelines on the use of genomic data and ensuring the quality of genomic data for the widest possible further use of data. As genomic data is produced in many different ways, it is essential to understand the purposes for which genomic data produced using different methods can be utilised in general. Genomic data must also be harmonised and updated (e.g. updating to new genome versions). Providing genomic data for further use in RDI activities requires resources, but enables new innovations and their further implementation into new products and services. This measure requires solving questions related to the storage format and storage location of genomic data.

**MEASURE 4:****Assessing the impact of the utilisation of genomic information**

There is plenty of international research data on the effectiveness of genomic information used in clinical work. As with the introduction of new forms of diagnostics or treatment in general, the effectiveness of the utilisation of genomic data in the prevention and treatment of illnesses must be demonstrated on the basis of data researched in the Finnish health care system. The impact of the utilisation of genomic data in the Finnish health care system in the prevention and treatment of illnesses can be studied with the help of pilot studies, which is at the same time a good way of both implementing research data into operative activities and increasing the health care system's awareness of impact. On the other hand, an informed cost-benefit assessment is necessary to appropriately direct the distribution of resources.

**MEASURE 5:****Collecting information on existing solutions in the Finnish health technology sector and their use in connection with the utilisation of genomic information**

Mapping of technological solutions related to genomic information used or under development by health technology companies. It will also be examined what kinds of user experiences have been gained in clinical work. By identifying solutions in use and under development, it is possible to ensure the full utilisation of the various possibilities available. The study will also provide information on how Finnish companies in the genome field could be helped to succeed internationally and what kind of operating environment would enable success.



## Strategic goal 2:

### Knowledge of the current state lays the foundation for utilising genetic information in health care and promoting people's welfare

Genetic information could be utilised more extensively at different levels of health care. In practice, this means the use of the latest genetic research methods and the active application of the data collected from them for the benefit of health care clients. In order to make more extensive use of genetic information in health care and to support people's welfare, it is necessary to examine the current state of utilisation of genetic information. In addition to the situational picture, it is important to map out future needs and resources related to the utilisation of genetic data and to monitor the international development of the utilisation of genetic data, aiming at international cooperation. The above-mentioned information collection measures are carried out under the leadership of the Genome Centre together with an expert group and stakeholder panel formed in connection with it.

Expanding the utilisation of genetic information in health care requires information on cost-effective genetic studies in different indications and health care information systems that enable the utilisation of genetic information. In addition, skilled professionals are needed who are able to apply genetic information in patient diagnostics, treatment, monitoring and counselling (e.g. bioanalytics experts, experts interpreting genetic data, genetic specialisation and other health care personnel). In order to promote the utilisation of genetic information, the Genome Centre must also produce services intended for health care professionals and, for its part, strive to strengthen the population's understanding and literacy of genetic information.

#### **MEASURE 6:**

##### **Examining the current state of the utilisation of genetic information and the practical possibilities of applying it in primary health care**

The current readiness of primary health care to utilise genetic information, carry out genetic studies and carry out carrier studies with gene tests will be mapped. The report makes it possible to assess the application of genetic information in primary health care, for example, in the pharmacogenetics of patients with multiple medications (or more broadly in the field of pharmacogenetics) and what kind of support would be needed for the utilisation of genetic information. It would be possible to examine the usefulness of carrier screening of people over 18 years of age by means of pilot studies, for example in student health care.

**MEASURE 7:****Examining the current state of the utilisation of genetic information in specialised medical care**

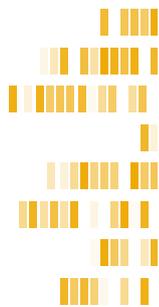
The implementation of extensive and cost-effective utilisation of genetic data in specialised medical care in a few disease groups will be examined. Clinical use cases will provide a realistic picture of the current use of genetic studies in specialised medical care. The assessments will help to evaluate the extent of the use of genetic studies, the types of studies used and their cost-effectiveness. The assessments can be directed at one or more specialised medical care units. Possible subjects of the studies may include the systematic utilisation of genetic data in care in cardiology units or in examinations of patients with delayed development in genetic medicine.

**MEASURE 8:****Examining the need for additional training in genetics**

A study will be carried out on the additional training needs of genetics professionals based on the predicted growth in the utilisation of genetic data until 2030. The impact of the study on promoting the utilisation of genetic information is significant. The study must take into account the need for further and continuing education of both genetics professionals and other health care professionals. In connection with the study, the training volumes and content of training for health care professionals required for the utilisation of genetic information will be assessed.

**MEASURE 9:****Drawing up and implementing a plan to strengthen the population's understanding and literacy of genetic information**

A plan will be drawn up to promote the understanding and literacy of genetic information among citizens, based on reports on the extent and needs of the use of genetic information carried out in measures 6-8. The implementation of the plan will be promoted through various communication methods as part of the Genome Centre's activities in cooperation with various parties. This enables the provision of correct and accurate information to the population and the initiation of a citizens' dialogue on various issues related to the use of genetic information. Strengthening citizens' understanding of genetic information is expected to reduce possible prejudices and fears related to the utilisation of genetic information.



## Strategic goal 3:

### Solutions that take the development of the field into account are applied in the production and management of genome-wide data

In order to produce and utilise genome-wide data (genomic data) in the most appropriate and efficient way possible, various structured information production and information management processes are needed to support it. Issues related to the storage of genomic data and the analysis environment must be resolved nationally, taking into account international development and policies. Storage solutions for genomic data affect the usability of genomic data in various later uses. In terms of definitions, quality criteria and operating methods related to genomic data, national standardisation work is still required, which the Genome Centre can promote in its coordinating role.

The development of the quality, quantity and use of genomic data produced should be monitored and steered at the national level. The purpose of the wider utilisation and sharing of health information (including genetic information) is to promote new observations and the accumulation of general understanding. In the future, it is necessary to define what kind of genomic data related to care practices is legally permitted to be shared between different health care units. At the moment, for example, in rare diseases, information does not accumulate, which emphasises the importance of exchanging and sharing genetic information even at the global level. The wider use and possible further use of genomic data produced by scientific research for clinical purposes requires the development of various minimum quality requirements and the drafting of legislative specifications, taking into account the GDPR, medical device and IVD device regulations in force.

#### **MEASURE 10:**

##### **Determining the production and interpretation capacity and quality requirements of genomic data**

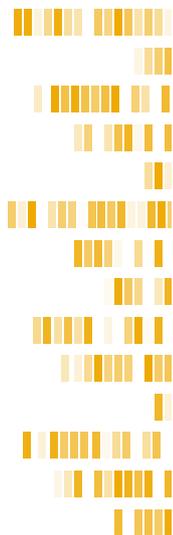
From the perspective of both clinical work and scientific research, the amount of genomic data needed in the next 3 to 5 years will be assessed and the adequacy of the required laboratory resources and interpretation capacity will be mapped in order to meet the production needs assessed in Finland. The report makes it possible to assess possible needs for additional resources for laboratory tests and to direct various solutions related to these. An assessment of the cost-benefit ratio based on information and health economics is still required for the appropriate steering of resources.

**MEASURE 11:****Producing solutions to questions related to the storage of genomic data and the analysis environment**

Concrete proposals for solutions, including cost estimates, will be produced for issues related to the storage of genomic data and the analysis environment, taking into account international policies and development. These solutions require a lot of resources, but their impact on the utilisation of genomic data is significant.

**MEASURE 12:****Anticipating the extent of the production and use of genetic information needed in future health care**

An assessment and a proposal will be prepared at national level on the extent of the production and use of genetic information needed in future health care in the coming years. The assessment is based on studies carried out in measures 6, 7 and 10 on the extent of the current use and production of genetic data. The proposal contains grounds for the production of genetic information and the extent of its use as well as a description of who the information is produced for. In addition, a proposal will be prepared for future funding for the production and use of genetic data.



## Strategic goal 4:

### Fluent utilisation of genomic information is possible in an ethically sustainable manner

The massive increase in knowledge of the human genome and its significance opens up new opportunities for health promotion and treatment of illnesses. At the same time, the new data mass that has emerged as a result of processing and combining enormous amounts of data creates numerous questions about the justification and limits of its utilisation. Even today, genomic information is produced and utilised extensively in the world, but an enlightened society strives to do this in a controlled manner that promotes people's health and respects their rights. The utilisation of genomic data requires a shared view of ethical principles and the construction of an enabling operating environment. The many dimensions of the use of genomic data require discussion and exchange of views between various parties in society. In order to ensure the right number of required professionals, the level of education and optimal placement, there is a need for mapping training needs, updating training plans, etc. An essential part of the enabling national operating environment is also active participation and advocacy in international activities as well as the maintenance, development and creation of various international cooperation networks to support national activities and to utilise the opportunities offered by international cooperation.

#### **MEASURE 13:**

##### **Establishing a centre of expertise to bring together and refine national genomic expertise**

Numerous questions related to the processing and utilisation of genomic data can be resolved by gathering national expertise and concentrating it in one centre of expertise, the Genome Centre. The task of the Genome Centre is to act as a national expert authority in matters concerning the processing of people's genetic data and genetic analyses related to health. The activities of the Genome Centre are based on existing national operators in the field, and the key objective of its activities is to strengthen cooperation networks and synergies at the national level. The tasks of the Genome Centre serve the achievement of health benefits and are thus closely linked to the reform of the operating models of social welfare and health care. A prerequisite for the success of the tasks assigned to the Genome Centre is securing realistic resources to launch and maintain its operations.

Statutory expert roles for the Genome Centre	
1.	Make recommendations within the scope of the field of its duties.
2.	Develop network-based stakeholder cooperation and regional activities.
3.	Provide general guidance for citizens.
4.	Work to promote societal discussion related to genetic information and genetic analyses, as well as research and education in the field.
5.	In addition to paragraphs 1-4, work to support responsible and equal processing of genetic data for the benefit of people's welfare and health.
6.	Participate in international activities in accordance with its duties

#### Other duties for the Genome Centre:

- Developing, evaluating and updating ethical principles
- Monitoring the needs for legislative amendments and participating in the preparation of possible legislative amendments
- Participation in the debate on the introduction of new technologies and diagnostic methods
- Monitoring national strategic guidelines and adapting the Genome Centre's work to them
- Drafting a national level proposal on the scope of genomic data production and use
- Participating in the storage of genomic data and solving questions related to the analysis environment
- Participation in the definition of minimum quality requirements for clinical genetic tests
- Mapping different funding models for genomic data production in cooperation with other operators
- Promoting cooperation with the Genome Centre and other national centres of expertise
- Creating an operating environment for Finnish genomic companies that supports international growth
- Attracting international business and research activities to the Finnish market.

## MEASURE 14:

### Appointing a group of experts in genomic medicine to support the operation of the Genome Centre and creating a network-based operating model for the Genome Centre

Due to the nature of the duties of the Genome Centre, it needs multidisciplinary expertise and expertise in a number of areas, including genetics, genetic medicine, gene technology, public health, ethics, data analytics, data security, data protection, cybersecurity, genetics research, law and statistics. In order to safeguard this diverse expertise, a group of genomic medicine experts consisting of experts on various topics will be appointed. Its task will be to prepare and maintain a separately established stakeholder panel on the processing and utilisation of genetic data, which is central to the Genome Centre's operations (see measure 3). The primary selection criterion for the members of the expert group must be strong substance expertise, while organisational representation remains secondary in this context.

The activities of the Genome Centre must be based on cooperation between Finnish experts organized in a network model. The role of the extensive and changing network

of experts is to participate in the activities of the Genome Centre by, for example, preparing various information-based recommendations and guidelines related to the utilisation of genomic information. The networked operating model enables the wide participation of different professionals across Finland and contributes to the implementation of jointly agreed policies in health care.

### **MEASURE 15:**

#### **Setting up a stakeholder panel**

A separate stakeholder panel will be established to enable diverse societal discussion and to take into account the opinions and views of different operators in society (including the patient perspective). The focus of the panel's activities will be on active participation in society and strengthening opportunities for having an influence. One of the key purposes of the stakeholder panel is to promote and maintain discussion on ethical principles related to the utilisation of genomic data. Through the activities of the stakeholder panel, the Genome Centre also receives useful feedback to support and develop its activities. The aim of the stakeholder panel's activities is to build extensive societal participation and trust, which is why its composition must represent diverse groups of society (including citizens, patient organisations and other third-sector operators, genomic service companies, etc.).

### **MEASURE 16:**

#### **Mapping the level of national genetic competence and drawing up a plan for developing it**

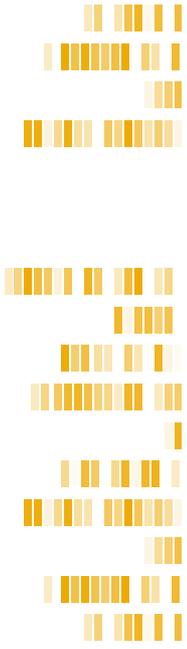
In order to promote the wider use of genomic data, it is necessary to map the current level of genetic competence of health care professionals and to ensure sufficient and optimal placement of the necessary experts and professionals. The survey is used to identify potential competence development needs and to draw up a plan for the national development of genetic competence through various professional education and training methods.

### **MEASURE 17:**

#### **Drawing up ethical principles related to the utilisation of genetic information**

The utilisation of health information (including genetic information) must take into account, among other things, respect for human dignity, ensuring the right to self-determination and the protection of privacy, equality of people and national and international legislation on the use of health information. This requires commonly accepted ethical principles, a clear legal basis that reflects them, and uniform interpretation of regulations. With its expertise, the Genome Centre must support this whole and initiate a process to define ethical principles related to the utilisation of genetic data.

When drawing up the ethical principles to be followed nationally, consideration should be given to various international principles that are widely used in the field of genetic medicine. It is important to bring the topics to be discussed in different international forums into national debate and, reciprocally, to bring the ideas resulting from the national discussion to international forums, thus promoting international principles that take national perspectives into account. In the future, the Genome Centre and its various expert bodies and stakeholders must regularly assess and, if necessary, update the ethical principles set for the national utilisation of genetic data. In addition to the ethical principles related to the utilisation of genetic information, ethical guidelines are also needed on how the patient is informed of the findings of any genetic studies carried out in connection with the patient's treatment.



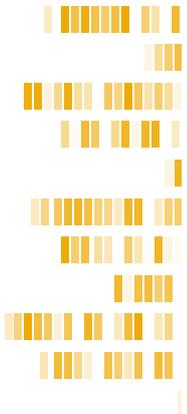
# Identified challenges

The use of genetic information in health care has become and continues to become more common. The potential benefits of successful utilisation of genetic data include disease prevention, targeted screening, advanced diagnosis, more personalised treatment, safer pharmacotherapy and more impactful research. In the future, health promotion and treatment of illnesses will probably be increasingly planned individually with the help of information obtained from the genome.

The operating environment related to the utilisation of genome and health information is extensive, complex and partially in a state of change. In this context, certain challenges, dissenting opinions and a number of questions were identified and presented in connection with the genome strategy update process. The issues raised were, in particular, related to the necessity and role of the Genome Centre to be established as an authority and the justification for the national genomic information register planned for a later stage. During the update process, various experts also presented alternative operating models for the establishment of the Genome Centre and the necessary national coordination. There was consensus that if sufficient resources are not ensured for the Genome Centre's operations from the outset, there is a risk of failure in the implementation of the planned duties and in the implementation of the measures presented in the genome strategy. This might result in a more difficult operating environment than the enabling operating environment, from the perspective of both individual and research utilisation of genomic data.

The differing expert views presented during the updating of the genome strategy were related to the secondary use of gene sequence data produced in diagnostic studies for purposes other than the treatment of the patient in question. Some of the experts also emphasised that the role of genomic information in the anticipation, management and prevention of several common diseases has proven to be more complex than expected. Experts support rapid changes to the genome strategy and legislation related to genomic information when necessary. In future updates, it is essential to take into account changes in the operating environment, sometimes occurring rather quickly.

Several open questions related to the utilisation of genetic data were identified during the genome strategy update process, but it is not yet possible to find unambiguous answers and the required solutions to these questions. These questions and topics are related to, for example, the storage of genomic data, the funding base for genetic analyses and the needs of different stakeholders. Experts emphasise the importance of resolving these issues in the future. Genetic information is already used for many different purposes globally and also in Finland, and it is of interest to many different parties in society. This interest is more likely to increase than decrease in the next few years. In order for the utilisation of genetic data to lead to better welfare and health in an ethically sustainable manner, we need national strategic principles and policies on the processing and use of genetic data. This is most natural through the establishment of the Genome Centre and the careful planning of its duties. The genome strategy update process has provided opportunities for dialogue between operators in the field, for opening up different perspectives and for exchanging opinions and views. Such discussion should continue to be actively encouraged in the future.



## Conclusion

In order to realise the vision “*Better health through the use of genomic information*”, we need a party that takes care of implementing the vision. Several measures have been proposed in this update of the National Genome Strategy, some of which include carrying out studies related to the use of genetic information. These studies will deepen our knowledge and understanding, which in turn will help to solve the challenges identified above.

The future Genome Centre is a natural party in launching the measures presented in the genome strategy. In cooperation with national experts, the Genome Centre will draw up national principles and policies for evidence-based and ethically sustainable utilisation of genetic data. This will both create preconditions for residents’ equal opportunities to benefit from genetic information and support medical professionals in their work. For example, genetic data can be used to better identify cancers and their causes, which will enable targeted and more personalised treatment and reduce the harmful effects of pharmacotherapy. The prevention of diseases can also be improved with the help of genetic data, for example, by focusing monitoring on carriers of gene alterations manifesting an increased risk of illness, as is already the case with, for example, high-risk breast cancer. The Genome Centre can promote research and development by promoting the harmonisation of extensive materials. Harmonised data also enable new innovations by advancing the application of research results to develop health-promoting products, services and operating models.

More extensive use of genomic information to promote health is currently attracting international interest in researchers, health care professionals and decision-makers alike. It is important that Finland actively participates in these international activities, discussions and policies, as we are pioneers in many solutions and practices related to genetics. As a national authority, the Genome Centre can act as a Finnish contact and representative in various international initiatives, such as the European 1+MG (1+ Million Genomes) initiative.

At its best, a new, dynamic, multidisciplinary ecosystem promoting the use of genetic information can be built around the Genome Centre, bringing together experts, decision-makers and citizens. Many parties will benefit from the activities of the ecosystem, in addition to which it can promote societal discussion related to the use of genetic information and thus promote the creation of a shared view of how genetic information can best be utilised in Finnish society to promote better treatment of illnesses, health and welfare.



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