ACADEMY OF FINLAND

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Personalised Health – From Genes to Society

1 Background

The Academy of Finland's research programme Personalised Health explores the application of genome and other personal health data to maintain and promote an individual's health and to prevent and treat diseases. In addition, the programme will look into the technological, judicial, ethical, social and societal issues and impacts with regard to the collection, storing and use of such data.

The research programme is centred on the concept of *personalised medicine*, a new, comprehensive line of health research that is changing healthcare all over the world. Personalised medicine involves a completely new approach to understanding, categorising, diagnosing, preventing and treating diseases and promoting good health. This approach is based on the definition of an individual's genome, its function, cellular biochemistry and physiology, as well as on the utilisation of this information in individual medical treatment, disease prevention and nutritional profiling. Personalised medicine has revolutionised medicine and health in particular thanks to developments in genetic engineering and analytical and IT-based biomolecular science. An in-depth knowledge of individual health factors can help in targeting drugs and treatments correctly to those that need them. In a broader perspective, personalised medicine also helps in charting and identifying a person's lifestyle and environmental factors in order to use these in individually targeting health and nutritional guidelines and, at the same time, promoting physical activity and personal responsibility for health management. In addition, knowledge of personal health factors can give rise to excellent new tools and innovations in the area of pharmaceutical technology.

The development of individually tailored technology enables a much closer monitoring of patients, for example, during treatment or medical procedures. Compared to the current situation, this will require better and more precise devices and instruments, such as imaging and image analysis technology and smart sensors. It will also require new IT-based products and systems designed from a user and client perspective. The development of personalised medicine and healthcare also rests on the development of computer-aided adaptation of conclusions and recommendations, a process that combines health and illness data with molecular data, and secure long-term data storage with reliable rights management. This technological reform will also highlight the importance of expert health personnel and ongoing training.

The personalising of medicine and healthcare also gives rise to issues not directly related to medicine or technology, issues that will often necessitate a shift in mindsets, methodologies and practices. Active personal involvement by an individual in their treatment is an example of this shift. Many of the emerging issues have to do with the position of patients and clients, understanding the special characteristics of genetic information, and various ethical, moral, judicial and economic dimensions. When healthcare is made to emphasise the patient's autonomy and participation in planning treatment, there is a need to define the actual leeway given to the patient, especially in cases where the person's genome contains risks. Also other important issues and questions emerge: How do we talk about the risks involved with small children, their parents or people with difficulties understanding such information? Will the increasingly accurate genetic profiles stigmatise people? How do we deal with the confidentiality and ethics concerning access to genetic profiles? Can genomic characteristics endanger the equal treatment of people in society? What real opportunities do individuals have to comprehend the benefit of having complex genetic data on themselves? With an increased amount of data, what will happen to the quality of life? Will genetic testing, and even genetic guidance, be available to all? Who will be responsible for data interpretation, possible interpretation errors and the consequences of such errors? These are all essential questions that require careful and comprehensive discussion as well as all-round research including scientists and experts from a wide variety of disciplines.

On the other hand, with the ever-rising costs of healthcare, society cannot afford not to introduce potentially cost-saving solutions. That is why it is important to assess and explore both the opportunities and the weaknesses of personalised health as widely as possible. At the same time, it is important to ask what kinds of new methods and tools genetic data can provide so that individuals can control their own lives and strive for a more equal therapeutic relationship with healthcare professionals, and also what the reforms demand from society. How will societal

institutions and systems respond to this great transformation? The reform will require a thorough discussion about genetic databases, data storage and availability, and the judicial and socio-cultural factors related to such data.

2 Objectives

The research programme will be implemented in the best interests of basic research and to help individuals and society benefit from using genetic information and genetic health data.

The research programme will provide funding to genuinely multidisciplinary consortia that bring together different scientific disciplines with a view to unearthing new kinds of research perspectives. These multidisciplinary approaches can refer to, for instance, studies that move from basic research to research targeting individuals, the healthcare system, business companies or society at large while reformulating existing operating models and concepts.

The funded projects will make good use of Finland's unique genetic population, its favourable societal conditions (e.g. high level of education, well-working healthcare system, advanced technology, legislation and attitudes among the population) and the country's highly advanced databases and registers.

3 Themes

Medicine has always been based on a personalised approach. Personalised medicine, however, which involves the testing of molecular-level characteristics and an emphasis on predictive treatment, goes much further than that. It refers to a comprehensive shift in people's and society's attitudes and actions. **The first and foremost theme of the research programme Personalised Health is to produce data and tools to contribute to the understanding of individual characteristics at molecular level, and to using these data and tools for health promotion.**

Complex issues related to rights, obligations and responsibilities, and how these are divided between individuals and society, require active research. **An important theme of the research programme is to study and analyse the technical, judicial and ethical aspects of collecting and integrating data on individuals using methods of biology, medicine, social sciences, psychology, philosophy, computing analysis, legal science and economics.** This encompasses a versatile analysis of the changing status of patients and clients as well as a broad-based evaluation of data usage and availability issues from a judicial, psychological and socio-cultural perspective. Personalised health is an important research theme from a societal viewpoint as well. For instance, what are society's duties and responsibilities in terms of personalised medicine?

Personalised medicine calls for opportunities to compile and process large amounts of data. Gene charts, biobanks and registers form the basis of data collection and databases, but equally important are the individuals' opportunities to produce, store and control their personal data. **A key theme within the research programme is to facilitate advances in technology, data management and information systems, and biocomputing and bioinformatics to meet the needs of personalised medicine and health.**

4 Impact

Personalised medicine is a key research area worldwide, one that will arguably have great impact on both individual-level and public health. At present, personalised medicine is the target of much investment that will potentially yield breakthrough results in the application of basic research findings and the development of healthcare. This will entail a change from reactive to proactive healthcare: it will result in a move from (costly) disease treatment towards (inexpensive) early diagnosis and prevention. This change will give rise to new kinds of social, ethical and judicial issues for clients, healthcare professionals and policy-makers alike.

In Finland, the volume of research conducted in the field of personalised medicine is already significant, especially in medical research, technological research and research into genomic functionality. The knowledge and tools generated through this research are also of use in the pharmaceutical and diagnostic industry's research and innovation activities, as they inevitably improve cost-efficiency and enhance product and service development. In this respect, the Academy

of Finland's research programme Personalised Health will pool together cutting-edge basic research in different fields with a view to advancing health promotion.

5 Implementation

5.1 Funding

The Personalised Health Research Programme is a four-year research programme (2015–2019) funded and coordinated by the Academy of Finland. Through the programme, funding is provided to multidisciplinary research conducted by research consortia. A research consortium is a collaboration of independent fixed-term projects working under a joint research plan by combining different methods and research fields with a view to achieving greater added value than is achieved by normal project collaboration. The planned funding budget for the programme's first call is EUR 9-14 million.

5.2 National and international cooperation

In Finland, personalised medicine is also one of the key themes of Tekes' focus area *Vitality of People*. For example, Tekes has supported the Institute for Molecular Medicine Finland (FIMM) and hospital districts in the development of biobanks. Another example of the innovation potential of personalised medicine is Taltioni, a database and service platform developed by actors such as Sitra containing information on health and wellbeing for Finns, healthcare providers and producers of welfare services. Personalised medicine is also a key topic for SalWe, the Strategic Centre for Science, Technology and Innovation in the field of health and welfare, through its programme *Personalised Diagnostics and Treatment*.

The theme of personalised medicine is closely related to development needs in the healthcare system and to research infrastructures in the medical sciences, especially registers and biobanks. Finland is a forerunner in establishing, operating and developing such infrastructures, with not only significant national collaborations but also extensive international collaborations both in the Nordic countries and at EU level.

Personalised health is also a topical and significant research theme at the global level. In Europe, it is one of the priorities in Horizon 2020, the EU's new framework programme for research and innovation, where *Personalising Health and Care* forms part of the health section under the *Health, Demographic Change and Wellbeing* challenge. The EU programme will support research and innovation in healthcare with a view to improving personalised diagnostics, optimising drug therapy and treatment and controlling risks in order to promote healthy ageing, for instance. The programme covers many areas in relation to personal health data, such as treatment and self-care, predictive healthcare and studies on adaption to environmental change. The Academy of Finland's research programme Personalised Health will participate in EU programme activities and explore available funding opportunities.

6 Application guidelines and review criteria

The Personalised Health Research Programme provides funding for four-year consortium research projects. The funding period starts on 1 September 2015 and ends on 30 August 2019. The programme has a two-stage call. At the first stage, applicants submit letters of intent including short plans of intent (see guidelines in the Academy's September 2014 call for applications). The letters of intent are submitted in connection with the Academy's September 2014 call. The steering group will make a proposal to the programme subcommittee appointed by the Academy Board on projects that would best fit in with the programme aims on the basis of the letters of intent. The projects selected to proceed to the second stage (to submit full applications) will be notified of the steering group's decision in December 2014.

Applicants requested to submit full applications must prepare a complete research plan and submit it in the Academy's online services by Thursday 12 February 2015 at 16.15 pm. See the guidelines for full applications in the Academy's September 2014 call for applications. The full applications will be reviewed by an international expert panel. On the basis of the scientific review of the applications and considering the programme aims, the steering group will prepare a proposal to the programme subcommittee on the projects to be funded. The subcommittee will make the funding decisions in May–June 2015 at the latest.

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Any additional international joint calls will be carried out according to a separately agreed schedule.

The applications will be reviewed in line with the Academy's general review criteria for research programmes (see www.aka.fi/eng > Funding & Guidance > Review of applications > Guides for reviewers).

7 More information

This programme memorandum is available as a PDF download at www.aka.fi/pHealth > in English.

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