

CITIZENS AND THEIR GENOME

MY DNA, EVERYONE'S BUSINESS?

Genome analyses are now taking place in daily practice. This creates possibilities in terms of prevention, screening and treatment of diseases.

That is true even today, for example for people with a rare disease or patients with cancer. Tomorrow there will be many more.

However, these analyses do raise questions. What do I want to know about my genome, which means all the genetic material that I received from my biological parents? What medical and non-medical applications do we want to be supported? Who are we willing to share our genome data with? And for what purposes? Is privacy an issue?

In the fall of 2018 the KBF and Sciensano organised an in-depth citizens' forum on the use of genome data: 32 men and women, across the age spectrum and from diverse backgrounds, not experts in

genome science but experts on their own lives, experiences and opinions. These citizens spent three weekends in discussions, both as a group and also with stakeholders, people with personal experience and genome experts.

In their citizens' recommendations they encourage policymakers, people working in this area and all stakeholders to set a timeline for change, looking towards a future in which genome medicine is widely supported by society.

“We must answer the legitimate questions of citizens with conviction and confidence. Should we fail to do so, we could lose all credibility and goodwill towards genome science.”

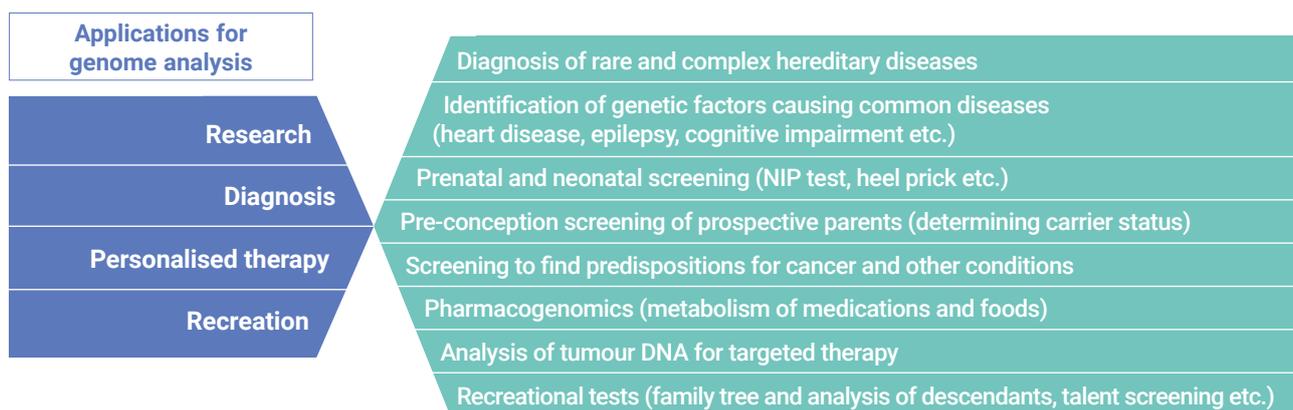
Reflection on the citizens' forum by the support committee.

AT A GLANCE

Until recently a genetic analysis involved only one or a limited number of genes. With technological progress, today hundreds of genes or even an entire genome can be analysed all at once. This is done both in hospital laboratories and genetics centres and also by commercial companies.

The Belgian Health Care Knowledge Center (KCE) in its report 'The use of Whole Genome Sequencing in Clinical Practice; Challenges and Organisational considerations for Belgium (2018)' mainly discusses

the organisational aspects of full sequencing. It looks at the clinical usefulness of specific analyses, interpretation and communication of results, data management, use of data for scientific research, privacy and the creation of an optimised organisational and financing system. The KCE study does not address any ethical questions. The ethical, legal and societal questions were entrusted to the Citizens' Forum, at the request of the Federal Minister of Public Health.



CITIZEN'S ADVICE

A citizens' forum

It is not easy for citizens today to come to a well-informed, well-considered opinion on complex questions facing society. Research looking at public opinion is often lacking in terms of reflection and depth. A well developed, deliberative group process like a citizens' forum meets this need. Researchers from KU Leuven attended this citizens' forum and assessed it as **'best practice'**.

The citizens' recommendations

• Towards a new kind of health care with changing roles

Genome analyses, when combined with other innovative technologies, will change health care. It is going to become more predictive and therefore more preventive. That will alter the status and rights of patients, or perhaps we should call them pre-patients? The roles of care providers will also change. There will be a need for new roles in health care. Even though GPs will continue to play an important cohesive role.

"If a genome test shows that I am at increased risk of having a particular condition in future, do I become a patient at that moment? Or a pre-patient? What am I then entitled to receive from the health care system?"

A citizen during the forum

• Sharing genome information for research, in the public interest

Citizens are willing to share their genome information for scientific research if this is done for the benefit of society. In their view, that research should enable us to understand human beings better, allowing us to work together to build a society that is fairer, provides more opportunities and encourages people to develop their full potential. They are also willing to collaborate in research that addresses the prevention and treatment of diseases.

• Making your own choices and decisions

People should be able to decide for themselves what they do and do not want to know about their genome. Written consent should be given before every genome analysis. Autonomy, however, is only possible if people are able to make informed decisions. So there is a need for the public, and certainly for individual applicants, to have more information about genome tests.

ABOUT YOUR GENOME

Your genome

is found in almost every cell of your body and it is the instructions for making you

It contains all your
22,000
genes

It is all
3,2 billion
letters of your DNA

My genome
was passed on to me
by my biological
parents



The analysis of an
entire genome can be
done in
1 day

1 genome
=
200 GB
information



enough to fill the memory of
an average laptop

A,C,T,G
are the 4 letters in the
DNA alphabet



• **Everyone must have access to genome tests**

Genome tests must not widen the existing health gap. Everyone who would benefit from them must have access to them. However, not everything that is technically possible should always be done, nor should it be done everywhere. Certainly not for tests that are reimbursed.

Citizens see the doctor as the first 'gatekeeper' to determine whether a test makes sense for an individual. On a higher level, a 'Council of Experts' was proposed which will draft criteria for the appropriate use of genome tests. Everyone is entitled to receive support before, during and after a genome test. Not only medical support, but also support with spiritual, relational, social and family aspects. A multidisciplinary approach is therefore needed and additional roles need to be created. Here citizens are thinking

of genetic counsellors, who need to have specific skills in all these areas.

• **Protecting genome information**

Most of the participating citizens want to retain control of the use of their own genome and health information. They want transparency, traceability and feedback. Who is using my data? For what purposes? And with what results? They also want to reserve the right to withdraw their data as soon as they have the impression that they are being misused. The use of genome data also must not result in discrimination or social or economic exclusion.

• **Flexible legislation and coherent policy**

Citizens expect the government to provide legislation that can be quickly adapted in line with developments in science, to protect them and their genome information and encourage scientific research which is in the public interest.

Genome science affects every area of life. Not only health, but also work, well-being, education, personal life etc. Citizens are therefore asking for a coherent policy across all the various areas and involving authorities on every level.

“We are more than just our DNA. There is a risk that people will say: ‘I have had my DNA screened. This, this and this is what I am.’ No, as a human being I am much more than my genome.”

A citizen during the forum citoyen

European survey

In parallel with the citizens' forum, the King Baudouin Foundation, ORB International and Gallup International organised a large-scale survey to find out the views of EU citizens on the use of genome information. Almost 30,000 EU citizens took part in the survey. This included 1,000 people in Belgium. A majority of Europeans (73%) and Belgians (68%) want to know everything about their genome and also want to share that information with their families (76% and 69% respectively) and with academic researchers (58% for both). A desire to share genome information with the pharmaceutical industry seemed to be less evident (40% and 41%)

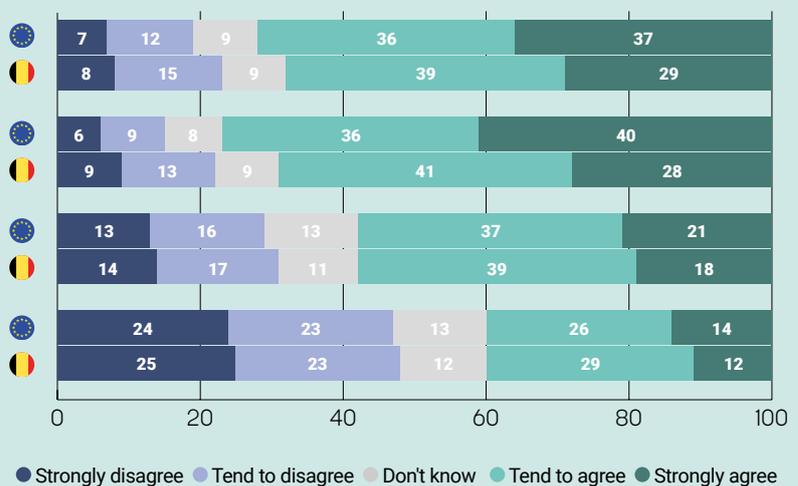
PUBLIC OPINION IN THE EU

I would like to know as much as possible about my DNA

I'm willing to share my genetic information with my family

I'm willing to share my genetic information with academic researchers

I'm willing to share my genetic information with pharmaceutical companies



n= 28,782
Weighted to be representative of the adult EU population

PRIORITIES FOR ACTION

The steering committee for the citizens' forum set out proposals for concrete action on the basis of the citizens' recommendations and an initial assessment involving stakeholders:

PREVENTION AND THE STATUS OF PRE-PATIENTS

Predictive genome tests will cause a greater switch towards a health care system that focuses on prevention. More research and reflection are needed to find out about the impact of this on the status of the (pre-) patient, on existing and new health care relationships, and on the health care system.

GENETIC COUNSELLORS

In the context of genome analyses, the traditional doctor-patient relationship must be reviewed.

There is a need for new functions to bridge the gap and more wide-ranging support. We therefore need to work on recognising and

training genetic counsellors. There is also a need to find out which other types of professionals and specialists in genome medicine need to be recognised.

GOVERNANCE AND INFORMED CONSENT

Citizens want their right to make autonomous decisions to be respected and they want to be able to make informed choices. This requires an in-depth analysis of information needs in relation to genome analyses, the development and implementation of appropriate informed consent forms and of tailored information tools.

Training for the professional groups who will be involved in genome analyses in future must include genome knowledge and counselling skills.

MULTIDISCIPLINARY COUNCIL

To ensure that genome medicine is guided in a direction that is socially

desirable, multidisciplinary consultation and coherent policy are needed. This consultation - in the form of a council or platform covering this whole area - must provide representation for all areas: medical, scientific, ethical, legal, organisational, health economics etc.

WIDE-RANGING DIALOGUE ON THE USE AND MANAGEMENT OF DATA

Citizens' major concerns about sharing data, data management, privacy, feedback and freedom of choice represent a major challenge, both for policymakers and for those conducting research. A wide-ranging dialogue needs to be initiated on the tensions between promoting scientific knowledge and protecting privacy and freedom of choice.

READ MORE

- **The use of genome information in health care : ethical, legal and societal issues** – Report of the Issue framing workshop, FRB, 2018
- **Mon ADN, tous concernés ?** Débat de société sur l'utilisation des données du génome dans le cadre des soins de santé, FRB, 2018
- **Mon ADN, tous concernés ?** L'avis des citoyens sur l'utilisation des données du génome dans les soins de santé, FRB, 2019
- **La connaissance du génome influence les soucis de santé,** Les citoyens demandent une politique pour l'avenir, FRB-Sciensano, 2019
- **Débat ADN, tous concernés ?** KBF-Sciensano

KING BAUDOIN FOUNDATION

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The King Baudouin Foundation is a public benefit foundation. The Foundation was set up in 1976 on the occasion of the 25th anniversary of King Baudouin's reign.

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