

UNDERREPRESENTATION OF MINORITIES IN GENOMIC DATABASES

Sara Martín García, Simon Alkema, Esmée Haenen and Niels Boersbroek

Genomic research should be for everyone.

However, our modern society is very diverse, and genomic databases are still **not representative for everyone** in society.

The current **Genome of Europe project** showcases this lack of equal representation of different ethnic groups.

HELP: what is a genome again?



A **genome** is the complete set of DNA (genetic material) of a person. While everyone's genome is unique, differences between people's genome are very small. Scientists combine the genomes of many people to create a **reference genome**, which is a representative average for those people.

BE CAREFUL! There is no genetic basis for race, it is a social construct. However, genetic differences do exist and they can affect diseases and drug effectiveness.

What is the GoE?

Initiative to combine reference genomes of European countries into a larger European reference database

Provide genomic data in an accessible database



Establishing **one reference genome** for each European country

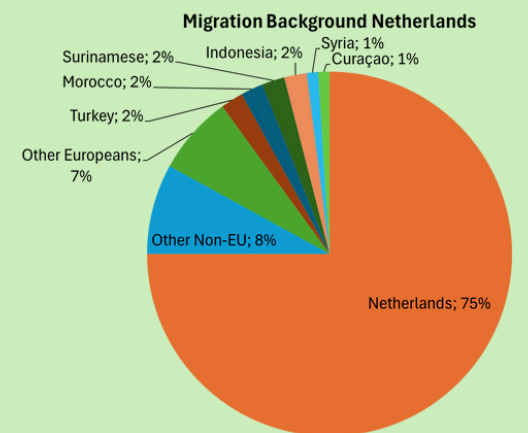
Improve genomics based research

Improve healthcare and make room for innovations

The problem with one reference genome

A lot of people will not be represented by the national reference genome

An example: The Netherlands*



There is genetic variance between different areas inside of the Netherlands

There are many Dutch people with roots outside of the Netherlands

*both these statements can be applied to every country in Europe

Consequences of lack of diversity



Misrepresentation of cultural identities can have **legal and economic consequences**, negative stereotypes can be reinforced



The underrepresentation of diverse populations limits genetic understanding and therefore leads to a **less accurate diagnosis**



There's a participation barrier due to **historical mistrust and systemic racism and discrimination**, this furthers polarisation



Structural barriers like lack of culturally sensitive strategies, **research focuses more on data rather than people**



The lack of representation leads to an **inequitable benefit distribution** as health disparities widen and the cycle of exclusion and inequity is reinforced

How do we make everyone benefit from genomic research?

- Advocating for **policies that promote inclusivity**, such as including information about genetic variation inside of countries in guidelines in the Genome of Europe project.
- Ensuring **representation** of marginalised communities.
- **Building trust** between scientists and underrepresented groups.
- **Raising awareness** in society and the scientific community.

Website of The Genome of Europe

