

Decoding nations: the EU's largest genome project Genome of Europe launched

- The Genome of Europe (GoE) project was initiated in response to the rapidly growing use of genetic data in research and clinical applications, and the lack of a whole genome sequence (WGS) reference dataset for Europe.
- The project brings together the ambitions of the <u>1+MG</u> initiative, the legal and technical framework developed by the <u>GDI</u> (Genomic Data Infrastructure) and genomic data providers to deliver a resourceful database for research and future clinical applications.
- The GoE kick-off meeting took place on 30—31 October in Rotterdam, the Netherlands.

27 countries join forces to establish a unique pan-European reference database comprising of a minimum of 100,000 genomes representative of European citizens

The most extensive EU-funded program on population genomics to date, "Genome of Europe" (GoE), has officially launched. The project partners convened in Rotterdam on 30 - 31 October to launch the largest EU program on population genomics in Europe called "Genome of Europe" (GoE). During the next 42 months this groundbreaking initiative will establish a unique pan-European reference database of at least 100,000 genomes to generate the reference genome through integration of genome datasets from diverse national populations – all for the benefit of personalised health care. The reference database will represent Europe's diverse populations, integrating existing genomic datasets and new genomic data through *de novo* sequencing of distinct national populations. The project encompasses 49 partners across 27 European countries (26 EU + 1 non-EU) and is backed by €45 million in funding with 20 million coming from the EU under the Digital Europe Programme by the European Commission.

The Luxembourg National Data Service (LNDS) will partner with the Luxembourg Institute of Health (LIH) within this European initiative, highlighting Luxembourg's commitment to genomic research and healthcare innovation.

While the LIH will contribute to the sequencing effort, bringing in Luxembourgish cohorts, the LNDS will contribute to defining ethical, legal, and societal conditions for generating the reference genome, ensuring data security, and embedding GoE data within the Digital Europe Programme-funded Genomic Data Infrastructure (GDI).

"LNDS leads the work package focused on the Ethical, Legal, and Societal Issues (ELSI). Together with our international partners, we aim to address the ELSI topics around data collection, data governance, and lawful reuse in research, healthcare and policy making." explains Bert Verdonck, CEO at LNDS.

Key goals of the GoE initiative include:

- **Creating a Pan-European Community of Practice**: Establishing a collaborative community to support the reference genome project.
- Evaluate the long-term potential of genome sequencing in research and health care in Europe and beyond, including different sequencing technologies, such as long read sequencing, helping to uncover previously inaccessible "dark regions" of the genome.



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- Ethics, Data Security, and Legal Compliance: The project will be guided by ethical, legal, and societal considerations while upholding stringent data security standards, building (inter)national guidelines for the responsible use of WGS that leads to better healthcare for EU citizens.
- Embedding GoE Data within Europe's Genomic Data Infrastructure: Integrating GoE data into the previously funded Digital Europe Programme's <u>Genomic Data Infrastructure (GDI)</u> project, ensuring interoperability across initiatives.
- Assessing GoE's Impact and Usability: Through case studies, evaluating the project's contributions to understanding genetic diversity, enabling multi-ancestry imputation, and enhancing genetic risk profiling.

About Luxembourg National Data Service (LNDS)

Luxembourg National Data Service (LNDS) is a brand of PNED G.I.E. an organisation created by the Luxembourg Government, to implement Luxembourg's strategies in research, innovation, and digitalisation. LNDS enables value creation from secondary use of data, for public and private partners and supports the sharing and re-use of public sector data, in a trustable manner. The LNDS service portfolio includes know-how, capabilities, tools, infrastructure, and data services. Through efficient & responsible use of data and improving the secondary use of data, LNDS will support the acceleration of economic, ecological, and societal transitions. <u>www.lnds.lu | LNDS on LinkedIn</u>

Contact: Catharina Schram | Head of Communications & PR | Luxembourg National Data Service | media@lnds.lu

About the Luxembourg Institute of Health (LIH)

The Luxembourg Institute of Health (LIH) is a public biomedical research organisation focused on precision health and invested in becoming a leading reference in Europe for the translation of scientific excellence into meaningful benefits for patients. The LIH places the patient at the heart of all its activities, driven by a collective obligation towards society to use knowledge and technology arising from research on patient derived data to have a direct impact on people's health. Its dedicated teams of multidisciplinary researchers strive for excellence, generating relevant knowledge linked to immune related diseases and cancer.

The institute embraces collaborations, disruptive technology and process innovation as unique opportunities to improve the application of diagnostics and therapeutics with the long-term goal of preventing disease.

Contact : Arnaud d'Agostini | Head of Marketing & Communications | Luxembourg Insitute of Health (LIH) | <u>communication@lih.lu</u>



A brand of PNED G.I.E. R.C.S. C175 |TVA LU34458768 LU05 0019 7155 3689 2000

6, av. des Hauts-Fourneaux L-4362 Esch-sur-Alzette Luxembourg +352 260 207 info@Inds.lu www.**Inds.lu**