

GENOME MATTERS

March 2025 Issue 1

The newsletter of the Genome of Europe project

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The GoE project sets sail

More than 100 Genome of Europe project members and stakeholders celebrated the project kickoff in Rotterdam at the end of October 2024. The unique choice of an ocean liner for the event location symbolises the ambitious journey that the Genome of Europe project will undertake towards laying the foundation for genomics-assisted healthcare in Europe and beyond. *Story continues on page 2*.

We are on social media!

LinkedIn: https://www.linkedin.com/company/genome-of-europe/
Facebook: https://www.facebook.com/profile.php?id=61573848750261









We have come a long way since the first human genome was sequenced in 2003. In late 2024, the Genome of Europe (GoE) project launched, with a mission to build the largest pan-European dataset of human genomes to date, eventually consisting of 500,000 genomes. With the current budget, supported by the European Union's Digital Europe Programme, the project aims to reach a total of 100,000 sequenced genomes, representative of the genetic diversity found within Europe.

Over the next three years, GoE will collect and analyse whole genome sequencing data from thousands of individuals to build a unique data resource centered in Europe. This resource, known as a "reference genome", will accelerate medical discoveries and enable the rapid advancement of personalised medicine.

In its initial setup, the project combines the efforts of 51 partnering institutes from 27 countries within Europe. With a total budget of €45 million in funding, with €20 million coming from the European Union, the project will not only generate an essential medical resource but also establish technical infrastructure within partner countries, helping to level the playing field for scientific advancement across Europe.

Strategic collaboration between GoE and GDI

The GoE project aligns with the $\underline{1+\text{Million Genomes initiative}}$ and feeds into the Genomic Data Infrastructure (GDI) project, enabling access to genomic data across Europe for research, healthcare and public health policy purposes.

On 3rd March 2025, GoE and GDI announced the signature of a Memorandum of Understanding, which strengthens the collaboration between the two projects via free exchange of knowledge and participants. More information on this collaborative strategy can be found on the <u>GDI website</u>.

GoE activities get underway

The start-up phase of the project has seen formation and activation of the task teams. Work package leaders have set up (monthly) recurring meetings and coordinated the first milestones and deliverables, geared towards setting up crucial infrastructure for the project. Communication and file sharing occurs through a Teams environment with an underlying Sharepoint site, accessible to project members at participating institutes. The growing collection of materials and documents so far include templates for presentations, project overviews and timelines, with a project Handbook due at the end of March.

Professor André Uitterlinden, project lead, said: "After the preparatory work in the 1+MG working group 12 over the past few years we could prepare a great proposal after the funding opportunity offered in April 2024 and we were very happy to see it approved for funding in July 2024 and work towards starting this data-generation project in October 2024.

Since the official starting data of 1st October 2024, and our kick-off meeting end of that month, we have already made very good progress in activating the work packages and getting people on board. We indeed had a very stimulating GoE kick-off meeting in Rotterdam, The Netherlands, where we had an opportunity to see each other in person and further discuss our plans and experience the very wide support across the participating countries to make the GoE happen. There is plenty of energy and enthusiasm in the consortium, with an ever-increasing momentum as we start to create the first GoE WGS data.

I am also particularly pleased to see several countries outside of the European Union, such as Ukraine, Switzerland, Serbia, and Türkiye, expressing their enthusiasm and willingness to join this exciting and ground-breaking project. We are currently working together with our EU project officers to accommodate this expansion of the GoE community with additional countries."









Deliverables and Milestones achieved

☑ D8.1 and MS39: Establishment of the Ethics Advisory Board

The external, independent Ethics Advisory Board (EAB) will ensure that ethics issues are monitored in a timely and independent manner. The EAB covers the expertise of ethics of research with biological samples, biobanking, data protection and ELSI of genomics research. The Ethics Reports, submitted alongside GoE Periodic Reports, will provide a holistic overview of how ethical concerns have been addressed for both legacy databases and new data collection, beyond only compliance with data protection regulations and citizen engagement activities.

☑ MS1: kick-off meeting

The kickoff took place at the end of October 2024 in Rotterdam.

☑ MS32: Mapping the national stakeholders

Participants from UTARTU have produced a GoE Stakeholders document, containing a preliminary list of research communicators, journalists and other relevant stakeholders who will be both collaborators and recipients of GoE communication activities. This is a live document, available in the GoE Sharepoint WP7 channel, in which partners are invited to add their local relevant contact points.

Coming soon in the project:

- The GoE project website
- The GoE Project handbook
- The GoE network of national ELSI experts
- Materials for press conferences

...and much more!

Dates for your diary

- European Mathematical Genetics
 <u>Meeting (EMGM)</u>, Brest, France
 <u>8-9 April, 2025</u>
 Organised by Dr. Anthony Herzig,
 co-lead of GoE WP6, this annual
 meeting offers an informal
 environment to exchange ideas on
 the use of mathematical techniques
 in the field of genetics
- GoE annual meeting, Milan, Italy <u>Friday 23rd May, 2025</u>

 Further details will be shared with institute leads in GoE
- Get2Gether: The Genome of Europe and All of Us initiatives At the European Society of Human Genetics (ESHG), Milan, Italy Sunday 25th May, 2025, 14:15 15:45

 This Get2gether session at ESHG (24th 27th May) will promote networking and professional connections with introductory presentations and updates on both initiatives, followed by a Q&A session.

Good to know...

The <u>Genome of Europe Calendar</u> contains an overview of the dates of project meetings and outputs in the coming months.







Meet the coordination team

The coordinators of the GoE project are based at the Erasmus MC in Rotterdam, The Netherlands.



Prof. Dr. André G. Uitterlinden, PhD - Project Lead

Experience: Molecular genetics, population genetics, genetic epidemiology, GWAS, consortia, omics technologies

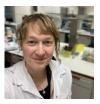
Favourite European City, area or cuisine: All of them! I love all good food and wine, and have a strong interest in history and culture, and I think Europe is the best place to live.



Dr. Jeroen van Rooij, PhD - WP1/WP5 lead

Experience: Bioinformatics and genetic epidemiology. Research includes polygenic risk scores and clinical use of genetics, such as in personalised medicine.

Favourite European Area: The DWS sites on Mallorca, Spain



Dr. Helen Ray-Jones, PhD - Coordinator

Experience: Computational and experimental research into complex trait genetics, using population genetics and functional genomics

Favourite European City: Antwerp, Belgium



Erwin Bovenkamp - Finance

Experience: 15 years of experience in financial advice and support to research departments at Erasmus MC

Favourite European City: Rome, Italy

The coordination team also gratefully acknowledge the work of **Wendy van Hemmen, Eline van Veen** and **Rayza Alphenaar** (all at Erasmus MC), who have been instrumental during project setup and provide ongoing advisory and logistical support.

GoE WP leads

Here are the leads and co-leads of the work packages in GoE. You will hear more from them in the coming issues of this newsletter

WP1 (coordination):

André Uitterlinden and Jeroen van Rooij (Erasmus MC)

WP2 (Samples and Technology):

Olaf Reiß (EKUT) and Ivo Gut (CNAG)

WP3 (ELSI):

Davit Chokoshvili (LNDS) and Olga Tzortzatou (BRFAA)

WP4 (Data infrastructure):

Anna Hagwall and Anna-Lena Ellasdotter (NBIS)

WP5 (Data collection):

André Uitterlinden and Jeroen van Rooij (Erasmus MC)

WP6 (Case uses and pilot studies):

Anthony Herzig (INSERM) and Astrid Vicente (INSA)

WP7 (Communication and dissemination):

Andres Metspalu and Merit Kreitsberg (UTARTU)

Contact us!

Report a **communication activity** on behalf of the GoE project <u>here</u>.

Do you have a question, or perhaps a story for the next GoE newsletter?

Contact us by email.



