



EUROPEAN SOCIETY OF HUMAN GENETICS

PEC REPORT 2024

Francesca Forzano, Chair

The Policy and Ethics Committee (PEC)

Outline



1. Activities, accomplished
2. Activities, ongoing
3. Activities, future
4. Business

Activities Accomplished 1/2

The use of polygenic risk scores in pre-implantation genetic testing: an unproven, unethical practice

Policy paper published EJHG (2022) 30:493–495, online 17.12.2021

Still Very high interest, many dissemination activities – first conference on polygenic embryo screening 2023, HUGO 2024

Note S15 Preimplantation genetic testing for polygenic conditions on Sunday June 3rd



22.05.2024

36 citations

ALL RESEARCH OUTPUTS

#14,465

of 25,709,917 outputs

OUTPUTS FROM EUROPEAN JOURNAL OF HUMAN GENETICS

#2

of 3,733 outputs

OUTPUTS OF SIMILAR AGE

#537

of 501,712 outputs

OUTPUTS OF SIMILAR AGE FROM EUROPEAN JOURNAL OF HUMAN GENETICS

#1

of 55 outputs

Activities Accomplished 2/2

Survey on Expanded Preconception Carrier Screening in Assisted Reproduction
in European MAR centers, a joint activity with ESHRE. Human Reproduction, *in press*
DOI: 10.1093/humrep/deae131

European Health Data Space - proposal for an opt-in system

Support in drafting the response of the ESHG on the proposal for an opt-in system for the use of genetic data for healthcare and research, and in lobbying with scientists and other societies in supporting the opt-out scheme.

Response to the WHO Invitation for Public Comments on the Draft WHO principles for human genome access, use and sharing

Comments provided were not in contrast with the core principles, but provided suggestions for clarifications, specifications and small implementations – for instance suggestion to add specific rules for communities consent.

Activities Ongoing 1/4

Cascade Testing: a strategy still underexploited across Europe? - *delayed*

Lead: Guido deWert

Ready for membership review

GDPR applied to human genetics (clinics, research) - *delayed*

Lead: Emmanuelle Rial-Sebbag.

Advanced draft, to be submitted summer 2024

Misuse of genetics for discrimination purposes – *delayed*

Lead: Yves Moreau

Advanced draft, to be finalised summer 2024

Activities Ongoing 2/4

Opportunistic Genomic Screening, survey

Lead: Heidi Howard

Scope: assessing impact of ESHG Recommendations in practice

Results available end 2024

Activities Ongoing 3/4

New Course: Covering The Gaps – The Course You Didn't Know You Needed

Co-Directors Francesca Forzano and Angus Clarke

Pilot on October 2024. Virtual, 2 days

Addressed to young scientists and clinicians

Topics: quality, regulation, research ethics, justice in diagnostics and research, data sharing and biobanks

Activities Ongoing 4/4

Workshop on Rare Diseases, Genomics and Justice.

Lead: Angus Clarke

Brocher Foundation grant obtained
Collaboration PEC – UK team (Ramona Moldovan) funded by MRC UK.
Will run January 2025.

The outcome of the workshop will be published on a special issue of the Journal of Community Genetics, including a meeting summary and key recommendations.

Activities, Future 1/3

Reporting in Prenatal Diagnosis

Lead: Sandi Deans

Joint activity PEC– Eurogentest - ISPD

Activities, Future 2/3

AI in genomics

Lead: Heidi Howard

Joint activity with GA4GH

External collaborators: Linda Battistuzzi

Activities, Future 2/2

Expanding Quality assessments.

Consideration for workshop.

New technologies– for instance gene editing, AI

Ethical implications of activities.

Sustainability.

Business - ToR

New **Terms of Reference** to be discussed at the PEC meeting on Saturday June 1st 2024. ToR will be integrated with two Annexes:

Annex 1: Conflict of Interest. To be specified: contents, format, visibility, archiving.

Annex 2: additional role of PEC to support the EJHG Board for selected complex ELSI, as agreed in 2023. **Lead Prof Maurizio Genuardi.**

Einstein Foundation Individual Award Winner 2023

YVES MOREAU



Photo: Lies Willaert

The Einstein Foundation Award for Promoting Quality in Research honours outstanding contributions to advancing the rigor, reliability, and transparency of research.

When it comes to human DNA research, Einstein Foundation Award winner Yves Moreau is an advocate for ethical standards. By drawing attention to potential abuses, he hopes to foster a cultural change in science and engineering education, encouraging researchers to consider the consequences of their discoveries.

Members of the PEC 2023/2024



EUROPEAN SOCIETY OF HUMAN GENETICS

Francesca Forzano (London, UK) - Chair

Carla van El (Amsterdam, The Netherlands) - Secretary General

Christophe Cordier (Lausanne, Switzerland)

Angus Clarke (Cardiff, United Kingdom)

Guido de Wert (Maastricht, The Netherlands)

Sabine Hentze (Heidelberg, Germany)

Heidi Howard (Uppsala, Sweden)

Milan Macek (Prague, Czech Republic)

Bela Melegh (Pecs, Hungary)

Alvaro Mendes (Porto, Portugal)

Yves Moreau (Leuven, Belgium)

Markus Perola (Helsinki, Finland)

Inga Prokopenko (Guildford, Surrey, UK)

Dragica Radojkovic (Belgrade, Serbia)

Emmanuelle Rial-Sebbag (Toulouse, France)

Rosaline Favresse (Paris, France)

Vigdis Stefánsdóttir (Reykjavik, Iceland)

Fiona Ulph (Manchester, UK)

Observers: Olga Antonova (Sofia, Bulgaria), Yalda Jashmidi (London, UK), Elena Avram (Bucharest, Romania); Rhys Dore (London, UK – ESHG-Y)