



EUROPEAN SOCIETY OF HUMAN GENETICS

PPPC REPORT 2023

Francesca Forzano, Chair

The Public and Professional Policy Committee (PPPC)

Outline



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

Activities Accomplished 1/2



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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

Activities Accomplished 1/2



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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

Reaction received by Tellier et al > response published Dec 2022

Very high interest, many dissemination activities - invitations to interviews on local televisions, talks at national and international conferences, university debates, book chapters



05.06.2023

24 citations

ALL RESEARCH OUTPUTS

#12,558

of 23,818,521 outputs

OUTPUTS FROM EUROPEAN
JOURNAL OF HUMAN GENETICS

#3

of 3,518 outputs

OUTPUTS OF SIMILAR AGE

#448

of 485,060 outputs

OUTPUTS OF SIMILAR AGE FROM
EUROPEAN JOURNAL OF HUMAN
GENETICS

#2

of 55 outputs

Demographic breakdown

Type	Count	As %
Members of the public	47	54%
Scientists	31	36%
Practitioners (doctors, other healthcare professionals)	5	6%
Science communicators (journalists, bloggers, editors)	4	5%

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Activities Accomplished 2/2



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IFHGS Congress 2023 Cape Town - session Privacy, consent and data sharing in the international genetic community

PPPC leadership, contribution of all the full members of the IFHGS and participation from GA4GH.

Excellent feedback, current consideration for a follow-up paper with contribution of all discussants

Activities Ongoing 1/5



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

Lead: Emmanuelle Rial-Sebbag.

In collaboration with Eurogentest Committee (Els Dequeker)

External experts: Deborah Mascalzoni, Colin Mitchell from PHG Foundation (Cambridge)

Aim: analyze the impact of the GDPR on genetic practice and research, offer some pragmatic guidance on the do's and don'ts

Advanced draft

Activities Ongoing 2/5



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

Lead: Guido deWert

Collaborators PPPC alumnae Lisbeth Tranebjaerg, Hülya Kayserili, Florence Fellmann

Aim: analyse barriers for implementation in practice and provide recommendations.

Advanced draft.

Activities Ongoing 3/5



Opportunistic Genomic Screening, survey

Lead: Heidi Howard

Scope: assessing impact of ESHG Recommendations in practice
Will be launched this week - ESHG2023

Activities Ongoing 4/5



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Misuse of genetics for discrimination purposes - *delayed*

Lead: Yves Moreau

External collaborators: Barbara Prainsack, Sam Riedijk (board member), Denise Syndercombe-Court, Gudrun Rappold, Veronika Lipphardt

Scope and aim:

- drafting some general **principles** for ethical conduct, illustrated by specific examples how practices involving genomic data can lead to unethical and undesired outcomes (misuse in terms of discrimination & exploitation)
- share and help discuss the lessons we can learn about these by formulating **recommendations** for institutions and individual conduct

Activities, Ongoing 5/5



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New ESHG course

Directors: Francesca Forzano and Angus Clarke

Title: *Things you need to know but nobody told you.*

Format: virtual, over 2 days. Approved by EC.

Purpose:

- Provide participants with information that is not generally taught in formal academic programmes
- Encourage participants to reflect on the importance of the 'how', including effective communication of research results/ new technologies/ treatments etc. to peers and lay public, and the importance to take into account the potential public perception of ethical and related 'political' issues in genetics
- Provide a framework on how to address ethical challenges in clinical or research settings.

Joint activities



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- **Eurogentest.** GDPR – PPC lead; Reporting in prenatal setting – Eurogentest lead
- **Education Committee.** Consideration on guidelines on best practice on the use of language when addressing patients with RD, to promote a more respectful and inclusive attitude. Workshop organised at the ESHG2023 conference (W08, Sunday June 11th).
- **ESHRE.** Expanded Carrier Screening survey. Closed 11.04.2022 (8 weeks); 338 replies received, 299 valid. Manuscript almost ready for submission to HR

Activities, Future 1/2



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Just Genomics : Avoiding harm and inequities arising from genomics
Lead: Angus Clarke, Carla van El, Heidi Howard.

Consideration for a document on AI in genomics.

Consideration for a viewpoint/position statement on feedback of results from biobanks.

Activities, Future 2/2



Widening the remit:

Strategy Committee

Incorporation of (Gen)Ethics Oversight Committee (GEOC)

https://www.eshg.org/news/news-details?tx_news_pi1%5Baction%5D=detail&tx_news_pi1%5Bcontroller%5D=News&tx_news_pi1%5Bnews%5D=34&cHash=827c9ec524487e97ecdf62b107616164



New name! Policy and Ethics Committee (PEC)

The Public and Professional Policy Committee (PPPC)

Members of the PPPC 2022/2023



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)

Edith Sky Gross (Barcelona, Spain)

Vigdis Stefánsdottir (Reykjavik, Iceland)

Fiona Ulph (Manchester, UK)

Observers: Olga Antonova (Sofia, Bulgaria), Yalda Jashmidi (London, UK),

Rhys Dore (London, UK – ESHG-Y)

<https://www.eshg.org/index.php?id=pppc>

The Public and Professional Policy Committee (PPPC)