PPPC REPORT 2023

Francesca Forzano, Chair
Outline

1. Activities, accomplished
2. Activities, ongoing
3. Activities, future
The use of polygenic risk scores in pre-implantation genetic testing: an unproven, unethical practice

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

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

Activities Accomplished 1/2

The Public and Professional Policy Committee (PPPC)
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.
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
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.
Opportunistic Genomic Screening, survey

Lead: Heidi Howard

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

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.

The Public and Professional Policy Committee (PPPC)
Joint activities

- **Eurogentest.** GDPR – PPPC 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
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)
Members of the PPPC 2022/2023

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