

Report of the Public & Professional Policy Committee



ESHG

Milan

17th June 2018

Martina Cornel, MD, PhD

Professor of community genetics
& public health genomics

On behalf of PPPC

Quality of Care

Community Genetics, Dept Clinical Genetics
EMGO Institute for Health and Care Research



The Professional and Public Policy Committee aims:

- To **identify and discuss the ethical, social and policy issues** related to human genetics and its application in research, clinical practice and laboratory genetic services.
- To be informed of various research projects, conferences and events, as well as policy initiatives and actions relating to those issues
- To **inform and stimulate the discussion** around these issues at meetings
- To address these issues and **provide guidance** through background documents, policy statements, recommendations or other publications
- To **participate in the public debate** around these issues
- To inform, interact with and provide advice to national and international policy makers

Activities 2017/18

- **Germline gene editing**
 - 3 papers appeared in EJHG: agenda setting, background document and recommendations together with ESHRE
- **Post mortem** genetics in sudden cardiac death
- **Recontacting**

Recommendations Post Mortem

Together with (and also endorsed by)

- International Academy of Legal Medicine,
- European Council of Legal Medicine,
- European Society of Cardiology working group on myocardial and pericardial diseases,
- ERN GUARD HEART
- European Association for Cardiovascular Pathology

Recommendations Post Mortem

1. Public health priority
2. Increase rate autopsy; mandatory under 40
3. Education
4. Medicolegal autopsies should have a dual aim (natural/crime; cause .. and allow results to be used for health care purposes for the surviving relatives)
 - Store sample for future DNA testing
 - Etc etc

Recommendations Recontacting

Building on earlier work of UK/Exeter and NL/Groningen groups, as reflected in authorship

In **clinical genetics**, recontacting for updating patients with new, clinically significant information related to their diagnosis or previous genetic testing may be justifiable and, where possible, desirable.

How to organize recontacting in current health care systems is a challenge.

Commensurate with **consent** previously obtained

Shared responsibility with patients/parents and lab

New topics?

- Opportunistic screening
 - Looking at more than initial clinical question
 - “56 ACMG genes” – when to provide additional information on actionable diseases?
- GDPR: what issues require clarification?
- Pharmacogenomics
- Testing children (revision?)
- Cascade screening/ informing relatives

New topics - continued

- IVD Regulation (David Barton *et al*)
- Genetics and law enforcement
- Consent and confidentiality
- DTC genetic testing

Members of the PPPC

	3-year term ends	Term
Christophe Cordier (Lausanne, Switzerland)	2020	1st
Angus Clarke (Cardiff, United Kingdom)	2019	1st
Martina Cornel (Amsterdam, The Netherlands) - Chair	2020	5th
Guido de Wert (Maastricht, The Netherlands)	2018	1st
Florence Fellmann (Dudelange, Luxembourg)	2018	2nd
Francesca Forzano (London, UK) - Co-Chair	2020	4th
Heidi Howard (Uppsala, Sweden)	2018	2nd
Hulya Kayserilli (Istanbul, Turkey)	2020	3rd
Bela Melegh (Pecs, Hungary)	2018	1st
Alvaro Mendes (Porto, Portugal)	2018	1st
Markus Perola (Helsinki, Finland)	2019	1st
Dragica Radojkovic (Belgrade, Serbia)	2018	2nd
Emmanuelle Rial-Sebbag (Toulouse, France)	2020	2nd
Vigdís Stefánsdóttir (Reykjavik, Iceland)	2020	1st
Carla van El (Amsterdam, The Netherlands) - Secretary General	2019	1st