Report of the Public & Professional Policy Committee

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

ESHG
Milan
17th June 2018
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
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
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
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<td>Christophe Cordier</td>
<td>Lausanne, Switzerland</td>
<td>1st</td>
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<td>Angus Clarke</td>
<td>Cardiff, United Kingdom</td>
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<td>Martina Cornel</td>
<td>Amsterdam, The Netherlands - Chair</td>
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<td>Guido de Wert</td>
<td>Maastricht, The Netherlands</td>
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<td>Carla van El</td>
<td>Amsterdam, The Netherlands - Secretary General</td>
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