Report of the Public & Professional Policy Committee

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On behalf of PPPC

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

ESHG
Paris
9 June 2013
Activities 2012/13 (1)

• Whole Genome Sequencing and Analysis recommendations:
  – Online summer 2012 to invite for comments
  – ESHG membership response integrated
  – Board approval dec 2012

Whole-genome sequencing in health care

Recommendations of the European Society of Human Genetics

Carla G van El¹, Martina C Cornel¹,²,³, Pascal Borry⁴, Ros J Hastings⁵, Florence Fellmann⁶, Shirley V Hodgson⁷, Heidi C Howard⁸,⁹, Anne Cambon-Thomsen⁸,⁹, Bartha M Knoppers¹⁰, Hanne Meijers-Heijboer¹¹, Hans Scheffer¹², Lisbeth Tranebjærg¹³,¹⁴,¹⁵, Wybo Dondorp¹⁶,¹⁷, Guido MWR de Wert¹³,¹⁶,¹⁷ on behalf of the ESHG Public and Professional Policy Committee
Activities 2012/13 (2)

- Whole Genome Sequencing and Analysis

Background document:

**POLICY**

The ‘thousand-dollar genome’: an ethical exploration

Wybo J Dondorp* and Guido MWR de Wert
Press coverage

What is next in the sequence.....???

- Several ESHG related activities to further develop guidance (esp. Laboratory protocols VUS, informed consent-EUGT)

- Debate

- Public awareness

- Education
Translation Genetic Tests Information Brochure Council of Europe, developed with Pascal Borry & PPPC; together with EUROGENTEST; distributed to public at large: Nat Soc Hum Genet websites, patients & parents organisations, secondary school teachers organisations, ...

http://www.coe.int/t/dg3/healthbioethic/Activities/07_Human_genetics_en/Brochure/default_en.asp
Myriad using clinical data to extend monopoly position

Privately owned genetic databases may hinder diagnosis and bar the way to the arrival of personalised medicine: ESHG reacts to today’s report in the European Journal of Human Genetics

Wednesday, October 31, 2012

In response to the on-line publication by the European Journal of Human Genetics today (Wednesday) of an article by US researchers led by Dr. Robert Cook-Degan, a former member of the US Office of Technology Assessment, showing that Myriad Genetics, providers of the BRCA1/2 genetic test in the US, has amassed vast quantities of clinical data without sharing it, Professor Martina Cornel, chair of the European Society of Human Genetics’ Professional and Public Policy committee, said:

“We are very concerned that such important data is being withheld from those who most need it. Etc.
Ongoing

- To be discussed June 2013:
  - Data sharing/patenting/business models
  - Preconception carrier screening
  - Post mortem genetics
  - Mental health
  - Prioritization & distributive justice (accessibility of genetic services)  *WS Nov 2012 Wolf Rogowski*
  - NIPT
  - etc
Your involvement…

- Policy making is never finished
  - Discuss WGA/S paper in your country, city, laboratory

Whole-genome sequencing in health care

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European Journal of Human Genetics (2013) 21, 580–584; doi:10.1038/ejhg.2013.46
Your involvement….

- Policy making is never finished
  - Discuss WGA/S paper in your country, city, laboratory
  - Some older policy documents remain relevant:
  - Newborn screening (supported by ESHG Board Oct 2011):

**A framework to start the debate on neonatal screening policies in the EU: an Expert Opinion Document**

Martina C Cornel, Tessel Rigter, Stephanie S Weinreich, Peter Burgard, Georg F Hoffmann, Martin Lindner, J Gerard Loeber, Kathrin Rupp, Domenica Taruscio and Luciano Vittozzi

Eur J Hum Genet advance online publication, May 8, 2013; doi:10.1038/ejhg.2013.90