

MEETING SUMMARY

Gene/Disease Specific Database Advisory Council & International Confederation of Countries Advisory Council
Friday 3 June, 2016
UNESCO Headquarters, Paris, France
1110-1300hrs Local



1. Welcome

Peter Taschner and Martina Witsch-Baumgartner, re-elected chairs of the Gene/Disease Specific Database Advisory Council and the International Confederation of Countries Advisory Council respectively, welcomed those members present in person and by teleconference.

2. Response to the Project Roadmap 2016-2020

a. ISAC Response

The Councils noted the response to *Project Roadmap 2016-2020* from the International Scientific Advisory Committee, specifically that:

the Human Variome Project's primary focus is on building medical genomics capacity in the health systems of non-advanced economies...[and]...that the objectives of the Project Roadmap will be achieved through the work undertaken as part of the Project-Wide Initiatives.

b. Council Responses

Having noted the response from the International Scientific Advisory Committee, the Councils together considered how they will respond to *Project Roadmap 2016-2020*. Noting that there were several areas of common interest for both Councils, it was thought that where possible, these issues should be pursued either jointly or with greater synergy. Specifically, the Councils resolved to:

- Merge the WG03 and WG07 Working Groups that have been working on defining minimal content criteria for gene/disease specific databases and HVP Country Nodes respectively;
- Develop strategies for bringing more people, particularly young people, and countries into the Human Variome Project Consortium, with a particular focus on demonstrating the value of the Human Variome Project in the everyday professional lives of people working in the genetics and genomics community;
- Review the methods that the Human Variome Project uses to promulgate the outputs of the Standards Development Process and encourage the adoption of HVP Standards and Guidelines more broadly;
- Develop a suite of tools (presentations, flyers, email templates, etc.) that Consortium members can use to deepen relationships between the Human Variome Project and national human genetics societies;
- Include a comparison table of available tools for variant data sharing in the Solution Blueprint;
- Provide guidance for members and the broader community on how the Human Variome Project defines variant data sharing—what it means to share data, ways to share data, the intended point of the different database classes;
- Seek further opportunities to work jointly so that the expertise and breadth of experience of Council members can be used more effectively.

In addition to these efforts, five HVP Country Nodes undertook to share data with one or more of the BRCA Challenge, InSiGHT, and Global Globin 2020, in the next six months. The Nodes making this commitment were:

1. Australia
2. Argentina
3. Italy
4. Canada
5. The Netherlands

3. Working Groups

a. WG03: Minimal content for gene variant databases (LSDBs)

Peter Taschner reported that work was continuing on defining the minimal content for a gene variant database. He reported on specific issues that were of concern, including a reliable means of recording information about the ethnicity of individuals that variants had been identified in.

b. WG07: Minimum Content of a Country Specific Variant Database

Martina Witsch-Baumgartner reported on recent progress and noted that the projected activities and timelines for this Working Group would need to be completely revised in light of the merger with WG03.

c. WG08: Ethics Checklist for Gene/Disease Specific Database Curators and Submitters

Rosemary Ekong reported that the Working Group was ready to move to the Consultation Stage of the Standards Development Process and would be writing to the ICO shortly to this effect.

4. Next Meetings

G/DSDBAC

- 12 July - Virtual
- 13 September - Virtual
- 8 November – Virtual

ICCAC

- 2 August 2016 – Virtual
- 4 October 2016 – Virtual
- 6 December 2016 – Virtual