



THE
HUMAN VARIOME
PROJECT
sharing data · reducing disease
an NGO Official Partner of UNESCO

MINUTES

International Confederation of Countries Advisory Council
23 May, 2014 – 11:15 – 13.00 CET
UNESCO Headquarters, Paris, France

HVP COUNTRY NODE REPRESENTATIVES INCLUDING NOMINATED ALTERNATIVES

Graham Taylor	Australia	Observers:	
Martina Witsch-Baumgartner (Chair)	Austria	Raj Ramesar	South Africa
Thomy de Ravel	Belgium	Peter Pearson	Brazil
Ming Qi	China	Johan den Dunnen	Netherlands
Maurizio Genuardi	Italy		
Zilfalil bin Alwi (Deputy Chair)	Malaysia		
Oyekanmi Nash	Nigeria	Richard Cotton (HVP Scientific Director)	
Maria Jesus Sobrido	Spain	Helen Robinson (HVPI Liaison – WHO)	
Sir John Burn	UK	Heather Howard (HVPI Operations Manager)	
Aída Falcón de Vargas	Venezuela	Timothy Smith (HVPI Communications Officer)	

AGENDA

1. Welcome

2. Apologies

See list above.

3. Welcome new Members

Several observers were welcomed to the meeting – South Africa, Netherlands and Brazil.

4. Confirmation of new council Chair

It was confirmed that Martina Witsch-Baumgartner was re-elected as Chair of the Council and Zilfalil bin Alwi was elected as Deputy Chair by the members present.

5. Confirmation of minutes of previous meeting – 25 March, 2014

The minutes were confirmed without change.

6. Issues arising from previous meeting

All issues arising from the previous meeting have been taken up in the items below.

7. Working towards 2016 HVP roadmap - role of ICCAC

The main item for discussion was to agree the key work priorities for the Council from now until HVP6 in 2016.

The following items were agreed as priority activities:

- a) **Developing a multi-country application for an EC Horizon 2020 grant** to provide an evidence base for co-operation on developing databases and sharing data in accordance with internationally agreed standards in the service of improving health care delivery in the context of personalized health care. As part of this process, it was hoped that an HVP regional co-ordinator/manager could be identified and paid as part of the application. An initial group of

countries will work together, including Austria, Spain, Italy, Belgium, Netherlands and Venezuela, and they will meet at ESHG in Milano next week to explore opportunities further. Other interested countries should contact the Chair if they would like to be involved. A further report will be made at the next meeting

Following the presentation by Diana Salmen of the EC the following links have been provided to help members gain further information regarding the full range of grants – deadlines, scope, objectives as so on.

Participant Portal provide all the information for applicants e.g. on how to participate

<http://ec.europa.eu/research/participants/portal/desktop/en/funding/index.html>.

The Work Programme and its general Annexes (including the list of countries eligible for funding) is on the Participant Portal:

http://ec.europa.eu/research/participants/portal/desktop/en/funding/reference_docs.html#h2020-work-programmes-2014-15.

Participant Portal is the entry point for expert registration too – any Council members who would like to assist in the application review process can find further information at the link below. Members are encouraged to participate in this process if possible to ensure that HVP principles of open access, transparency and ethical data sharing are promoted. Feel free to share this link with other colleagues in your organizations as relevant.

<http://ec.europa.eu/research/participants/portal/desktop/en/experts/index.html>

b) *Haemoglobinopathies and haemolytic anaemias*- developing a plan to establish country databases that can be federated and harmonized between now and 2016. It was thought that these important genetic diseases can provide a focus for node activity in several countries with a view to providing an internationally coordinated effort to apply genomic and genetic technical advances to tackling this disease burden. At the same time it could provide a concrete means for attracting the necessary funding from government or philanthropic sources to help link countries, particularly low and middle income countries. On this it was noted that, experience says that countries need to get started first with their own resources to establish a track record, before being in a position to be able ask for more financial support. Various ethical, social and regulatory issues will need to be addressed. An initial group of countries agreed to be involved in the preparatory discussions including: Mexico, Malaysia, China, South Africa, Nigeria, Portugal, Venezuela, Brazil and Belgium (together with DR Congo). Other countries interested in being involved should contact Helen Robinson at the ICO hmro@unimelb.edu.au before the next meeting. The ICO will do further background research on how this project might be advanced with the involvement of UNESCO, WHO and hopefully Sir David Weatherall. It was noted that Cyprus and Greece had done work in this area and so might be useful contacts. A short paper from 2013 Lancet on the global burden of these diseases is attached for information.

c) *Improving the quality of HVP Country Node's activities* – this overall objective will be addressed through two key activity projects:

- Developing minimum standards for HVP Country Node activity
- Determining the process for HVP Country Nodes moving from interim to full status

While these are separate activities it was agreed that they are closely related. The intention is to capture best-practice. It is expected that the two could be completed and agreed and be ready for implementation by mid-year 2016. Some preliminary work has been done on this by the ICO but the exact details of how these activities will proceed – who would like to be involved, timelines - will require further discussion at the next meeting.

d) *Producing a comprehensive HVP Country Node activity report*

Following the 2012 baseline survey it had previously been planned that a further report should be made on the basis on 2014 activity. Given the amount of work involved in other priority activities listed here, it was proposed that this should be postponed until 2015 and in the meantime, progress on Country Node activities be captured in the report format used in item 8 below. How this information could be analyzed to produce a comprehensive report will be discussed in 2015.

e) Capacity building

Various activities to improve skills and knowledge needed to establish and manage good quality country nodes were also suggested. A ICCAC plan should be developed to include appropriate education and training courses in national, regional and international society meetings. Topics could include Establishing and Running a HVP Country Node, use of LOVD, curation, application of standards and nomenclature, ELS issues, among others. Running these in conjunction with planned meetings should be financially beneficial to both national societies and HVP.

These listed activities will be put into a document format for further elaboration at the next meeting.

ACTION ICO to provide a draft document on the ICCAC Strategic Plan for 2014 -2016 for discussion and final agreement at the next meeting

8. Country Node updates

Thirteen written Country node reports were circulated to members. All submitted reports are attached. Members are thanked for their efforts in completing these reports in a timely manner and providing valuable information for the ICCAC on their current activities and challenges. These reports will be reviewed and a short summary provided for discussion at the next meeting. Members were encouraged to review each report before the next meeting.

ACTION ICO to provide a brief report for discussion at the next meeting
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9. Recommendations to the Scientific Advisory Committee

As mentioned in Item 7 above, the ICCAC priorities for 2014-2016 will be integrated into the overall ISAC HVP 2014-2016 strategy plan.

10. Other matters

It was noted that a Developing HVP Country Nodes Workshop was conducted on Monday 19 May at UNESCO. Initial feedback from participants and organizers indicated that this was very successful and of practical use for both those already linked to existing Country Nodes as well as those who are just getting ready. It was thought important that more opportunities for running this program should be identified.

11. Next Meetings - all via Calliflower unless otherwise indicated

- 29 July
- 30 Sep
- 2 Dec