



sharing data · reducing disease

an NGO Official Partner of UNESCO

MINUTES

International Confederation of Countries Advisory Council
4th February, 2014 - 11:10PM Melbourne, Australia time
Via Calliflower

ATTENDEES

Graham Taylor	Australia	Apologies	
Martina Witsch-Baumgartner (Chair)	Austria	John Coghlan	Australia
Thomy de Ravel	Belgium	Helene Antoine-Poirel	Belgium
Ming Qi	China	Milan Macek	Czech Republic
Augusto Rojas-Martinez	Mexico	Andreas Hadjisavvas, Maria Loizidou	Cyprus
Tilak Shresta	Nepal	Sherifa Ahmed Hamed	Egypt
Oyekanmi Nash	Nigeria	Mahmoud RaafatKandil	Egypt
Hadiza Mahey Rasheed-Jada	Nigeria	Makia Marafie, Fahd Al Mulla	Kuwait
Angel Carracedo	Spain	Zilfalil bin Alwi, Amir Feisal Merican	Malaysia
Maria Jesus Sobrido	Spain	Luis Figuera-Villanueva	Mexico
Andrew Devereau	UK	Rebati Man Shreshta	Nepal
ICO:		Myungchull RHEE, Jong Bhak	South Korea
Richard Cotton (HVP Scientific Director)		Sir John Burn	UK
Heather Howard (HVPI Operations Manager)		Mike Watson, Bruce Korf	USA
Timothy Smith (Communication Officer)		Aída Falcón de Vargas	Venezuela
Helen Robinson (HVPI Liaison – WHO)		Chí Dững Vữ	Vietnam
Fan Li (Liaison Officer)			

AGENDA:

Meeting Opened 11:10PM 4th February 2014 Melbourne time

1. Welcome

2. Apologies

See list above.

3. Welcome new members

No new members since last meeting.

4. Confirmation of minutes of previous meeting – 26th November, 2013

The minutes were approved without modification.

5. Issues arising from previous meeting

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

6. Country Node activities

6.1. **Country node updates: country node representative may give an update if there are new activities involving their node since the last council meeting**

PLEASE NOTE THE SECTION BELOW IS INCOMPLETE OWING TO THE POOR QUALITY OF THE MEETING RECORDING – A SEPARATE REPORT OF COUNTRY ACTIVITIES WILL BE SENT TO ALL MEMBERS

UK – with much of the national funding for databases finishing at the end of 2013, curators are starting discussions with Health UK on how to move these and other related activities, for example the rare disease register, into the mainstream health system. Discussions on how to co-ordinate better and develop sustainable funding models will involve Decipher, Genomics England and NHS.

Nepal – Dr Shresta reported that with the excellent support of the Malaysian node in providing training and other capacity building activities, work was progressing in two areas: thalassemia and colorectal cancer. There are concrete plans to include haemophilia next. The National Genetics Society was in the process of being re-established. Dr Shresta also asked if other members could provide him with further specific assistance on testing methods. A call for assistance will be added to the Consortium Up-date for next month.

Spain – indicated that a national meeting of the various stakeholders would be timely given the progress and changes occurring in the country and in the EU. Discussion of ways to avoid duplication of effort, to raise funds and improve networking and collaboration would be on the agenda

Australia – three quarters of the way through a 2 year project to connect Australian molecular data to clinical datasets using the BioGrid platform.

6.2. **Report on new nodes likely to be established in next 6 to 12 months**

Two countries have advised the ICO that they are in the process of establishing an HVP Node: South Africa; and Canada. A recent trip to ISHG in India resulted in establishing a high level group to pursue establishing a Node there. Another group of countries have been approached on the basis of their activity last year, including Italy, Netherlands, Portugal, Sri Lanka, Chile and Brazil. It was noted that with the new process for establishing an HVP Country Node starting in 2014, it was likely that the process would take a little longer from now on.

With the new category of 'Observer Status', Council members are reminded to mention that as an option when suggesting HVP membership to potential members.

6.3. **HVP Country Node Baseline Report: feedback about the country database from members**

Tim Smith gave members an up-date on the comments received so far on the country database and asked for further feedback before the next meeting. It is hoped that the database will serve members' needs and not just be a repository for information that is not very useful. It was noted that at this stage, members cannot up-date material directly themselves. While this function will be added once the format of the database is finalized, in the meantime, the ICO will provide this service. The country database has several roles:

- To promote sharing of information of activities occurring in each country
- To assist monitoring of level of variation storage and sharing occurring in different parts of the world
- To assist members prepare their base line reports – next is due at the end of 2014
- Act as a history of the development of variation data storage systems in various parts of the world.

ACTION: Using the link sent out during the meeting, Members to review the country database and send any additional material to ICO before the next meeting. The login and instructions were re-circulated.

7. Working towards 2016 HVP Roadmap

7.1. *Role of ICCAC: Discussion of attached action summary*

This item concerns the process of setting priority actions for the Council for the next two years. Members will be aware that HVP has a strategic document setting out the areas of activity for the period 2012 to 2016. As we are half way through this period, it is a good idea to review progress and refine activities for the next two years.

Marina Witsch-Baumgartner as Chair suggested some specific questions to shape feed back from members as the key priorities for HVP Country Nodes and the ICCAC for the next two years. The questions are aimed at forming consensus on the key tasks of the Council. The questions are:

- Which standards and guidelines will help countries participate? Which ones should be developed first?
- How should ICCAC members work together to monitor and improve compliance to HVP and other standards? How can we develop a system for monitoring?
- How can ICCAC encourage the development and use of open-source tools and systems?
- How can ICCAC improve knowledge and ethical practice among HVP Country Nodes?
- What specific workshops and so on can be organized and offered to promote the effectiveness of national clinical genetic databases? How to we work with pharmaceutical companies with out conflict of interest? How can these activities be funded?
- Other ideas, priorities?

These questions will be the basis for discussion at the next meeting, together with any others suggested before the meeting. This will then form the basis of discussions at the face-to-face meeting in May at HVP5 when a work plan for the ICCAC 2014 -2016 will be determined. Members are welcome to send their comments and suggestions to either of the Chairs or to Fan Li in advance of the meeting if they prefer, particularly those who may to be able to contribute on 25 March.

ACTION: Members to consider these questions in preparation for discussion at the March meeting

7.2. *Standards Development Process/Activity Proposals*

The discussion of strategic priorities linked into a discussion of the three draft proposals:

- 1 Draft Activity proposal CN-01-2014 - Standard/suggestion about content of a country specific database
- 2 Draft Activity proposal CN-02-2014 - Certification system of genetic/molecular tests
- 3 Draft Activity proposal CN-03-2014 - Funding of regional databases

There was support for the three Activity Proposals, particularly the minimum content requirements (CN-01-2014). This has been raised in discussion before. Following the suggestion, it was considered that a way of getting started on this process was for this Activity Proposal to be formally submitted to the HVP Standards Development Process. In the meantime, Andrew Devereau and Graham Taylor are to begin work on this by mapping the data models of the UK and Australian Nodes.

Regarding the certification of labs and tests (CN-02-2014), the general consensus was that it was not really the business of HVP to be providing such a service, but that the HVP could facilitate the development of these types of services in countries by sharing knowledge and best practices among members. This would provide an opportunity for countries to help each other by identifying potential partners for sample exchange.

With regard to CN-03-2014, there was a lot of interest in pursuing this topic but that perhaps an Activity Proposal was not the best mechanism to do this. Sustainability of funding is an issue that affects all members and one that needs more strategic attention. Following a general discussion, it was thought that members could think about the following in preparation for the next meeting:

- a. Possibility of identifying project funds that join several nodes to work together on developing standards, coordination of these activities – examples of possible programs for EU countries were suggested
- b. Improving co-ordination and collaboration of the national level through strengthening networks to avoid duplication and to identify opportunities for national and regional funding
- c. Pooling knowledge on what has worked in specific countries for raising funds for administration, national coordination, software development, database curation
- d. What kind of mechanisms would assist ICCAC members in identifying sustainable funding models as funding shifts from research projects to health care delivery in many parts of the world

ACTION: Call for Volunteers to join an interest group to scope the requirements of collecting, collating and sharing information on existing accreditation models for laboratories and specific tests in several countries. The results of this scoping exercise to be reported to ICCAC in May at HVP5. Volunteers to send their names to Fan Li before 25 March.

Draft Activity Proposal CN-01-2014 to be formally submitted to the HVP Standards Development Process.

7.3. Working Groups under the purview of the Council

No Working Groups under the purview of the Council

7.4. Interest Groups

No Interest Groups under the purview of the Council

8. Items for information

Not covered during the meeting.

9. Recommendations to the Scientific Advisory Committee

None

10. Other matters

10.1 HVP5

Due to connection issues Heather was not able to provide the verbal update and so this up-date has been provided for members.

We are pleased to confirm that H3 Africa will be presenting at the Meeting and we also encourage other countries to put in abstracts for the meeting as activities in developing countries is one of the key themes for the meeting.

There will be a joint meeting of this Council and the Gene/Disease Database Council and the International Scientific Advisory Committee in the late afternoon of Monday the 19th. This meeting will assist in making sure that the both promote dialogue between the groups and importantly it provides a platform to discuss our common issues and provides a basis for discussion throughout the week. On the Friday there will be meetings of both Councils, held in parallel in the morning, and the ISAC after lunch.

Please note HVP is unable at this time to assist with any funding for the councils or ISAC as we have still not received the promised funding from China and are awaiting outcomes from other applications and negotiations. If this situation changes we will let you know immediately. We hope that you will be able to attend and participate.

Elections for the new Chair will also be held at HVP5 and the Nomination forms will be sent out to all consortium members shortly.

11. Next Meetings - all via Calliflower unless otherwise indicated

25 March 2014

23 May - face to face, Paris

Meeting closed 12:10AM 4th February 2014 Melbourne time.