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MINUTES

International Confederation of Countries Advisory Council
25th March, 2014 - 11:10PM Melbourne, Australia time
Via Calliflower

ATTENDEES

Martina Witsch-Baumgartner (Chair)	Austria
Maurizio Genuardi	Italy
Domenico Coviello	Italy
Zilfalil bin Alwi	Malaysia
Oyekanmi Nash	Nigeria
Hadiza Mahey Rasheed-Jada	Nigeria

ICO:

Richard Cotton (HVP Scientific Director)
Heather Howard (HVPI Operations Manager)
Helen Robinson (HVPI Liaison – WHO)
Fan Li (Liaison Officer)

Apologies

Graham Taylor, John Coghlan	Australia
Thomy de Ravel, Helene Antoine-Poirel	Belgium
Ming Qi	China
Milan Macek	Czech Republic
Andreas Hadjisavvas, Maria Loizidou	Cyprus
Sherifa Ahmed Hamed	Egypt
Mahmoud RaafatKandil	Egypt
Makia Marafie, Fahd Al Mulla	Kuwait
Amir Feisal Merican	Malaysia
Augusto Rojas-Martinez	Mexico
Luis Figuera-Villanueva	Mexico
Tilak Shrestha, Rebati Man Shrestha	Nepal
Myungchull RHEE, Jong Bhak	South Korea
Angel Carracedo, Maria Jesus Sobrido	Spain
Andrew Devereau, Sir John Burn	UK
Mike Watson, Bruce Korf	USA
Aída Falcón de Vargas	Venezuela
Chí Dũng Vũ	Vietnam
Timothy Smith	ICO

AGENDA:

Meeting Opened 11:10PM 25th March 2014 Melbourne time

1. Welcome

2. Apologies

See list above.

3. Welcome new members

ICCAC welcomes Italy to formally become HVP Interim Country Node.

4. Confirmation of minutes of previous meeting – 4th February, 2014

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

Australia – The Australian Node is making good progress with more laboratories recently recruited; arrangement has been made to store the next generation sequencing data into the databases. Also locally based networks of researchers, clinicians and curators are being established to strengthen the Node.

Austria – Martina attended a meeting of National Genetics Societies of Germany, Austria and Switzerland, with attendance of approximate 800 people. The importance of database is well recognised. Some interesting ideas were discussed about type of database required and potential collaborations at the meeting (Martina will prepare notes and circulate). Potential funding opportunity is explored from the Austrian Ministry of Health for risk assessment of variant databases.

China – As reported in the international press, clinical genetic testing in China was suspended by SFDA and National Health and Family Planning Commission. The reason is to properly regulate this area of service with better registration and approval processes. It is recognised that the regulation is much needed as the field is growing rapidly, however the sudden suspension across the whole area has caused some immediate problems for both the service providers and patients. A meeting was held among about 30 experts and opinion leaders to discuss the issue. A suggestion paper was submitted to the government to assist with the process. The situation in China will be closely monitored and discussed within HVP in coming months.

Italy – The Node is currently working closely with the national Society of Human Genetics to establish its policies and procedures as a national node. The national government has recently released its strategic plan for genetics, genomics and public health and genetics. The Node will take this into account for its planning and promotion; it will also explore funding opportunities for use by Nodes like Italy who are for applying funding support from their governments.

Malaysia – With the help from Chris Arnold, Malaysia Node is in discussion with the Association of Southeast Asian Nations (ASEAN) to promote HVP as a collaboration initiative of all ten ASEAN countries. Malaysia Node is currently working on the proposal to be submitted to ASEAN in order to obtain funding support for the South East Asian Regional Node. The Malaysian government is fully supporting these efforts.

Nigeria – Nigeria Node is planning to formally launch the Node in May. Its representatives will attend HVP5 in Paris. Works on collecting samples, genotyping and bioinformatics analysis are in progress.

ACTION: ICO to prepare standard HVP presentation slides for Nodes; to provide supporting letters as requested.

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

A number of countries are actively in the process of establishing an HVP Node: South Africa, Brazil and Canada. Another group of countries are also indicated their interest in setting up HVP Node, including India, Netherlands, Portugal, Sri Lanka, Chile.

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 Reporting: feedback about the country database from members

Minor corrections were made according to the feedback from the members. ICO will proceed to make the database public within two weeks. It will be announced in the Consortium update.

It is planned that the country progress report will be requested every two years to collection information on genetic testing service, databases, policies, activities, and so on for each country. The next progress report will be based on activities of the period 2013 to the end of 2014, and so will be a major activity for next year.

ACTION:

- ICO to make the database public within two weeks and announce it in the Consortium Update.
- Using the country database link sent previously, members to review the country database and send any additional material to ICO.

7. Working towards 2014 - 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, reviewing progress and refining priorities for the next two years is very important.

Marina Witsch-Baumgartner as Chair suggested some specific questions to shape feedback from members as the key priorities for HVP Country Nodes and the ICCAC for the next two years:

- 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 this be monitored?
- 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 without conflict of interest? How can these activities be funded?
- Other ideas, priorities?

There are no additional questions and suggestions from members after the last meeting and during this meeting. These questions will be the basis for discussion at the face-to-face meeting in May at HVP5 when a work plan for the ICCAC 2014 -2016 will be determined.

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

7.2. Standards Development Process/Activity Proposals

Note that three activity proposals were discussed in the last council meeting. Proposal CN-01-2014 (Standard/suggestion about content of a country specific database) has been formally submitted to the Standards Development Process. Proposal CN-02-2014 (Certification system of genetic/molecular tests) and proposal CN-03-2014 (Funding of regional databases) are dealt under item 7.4.

7.3. Working Groups under the purview of the Council

No Working Groups under the purview of the Council

7.4. Interest Groups

7.4.1 Certification system of genetic/molecular tests

7.4.2 Funding of regional databases

It was agreed that these two items be taken up by small groups of interested members. The ICO will assist in coordinating these activities. It was noted that at HVP5 a representative of the EC will make a presentation about Horizon 2020 funding opportunities. Hopefully this will provide a mechanism for supporting inter-country collaboration for curated databases containing variation information. Members were encouraged to think about opportunities for countries to work together and submit joint proposals, and to include regional co-ordination roles. People who are interested in these issues may join the respective interest group to scope the requirements of collecting, collating and sharing information on existing accreditation models for laboratories and specific tests in several countries (7.4.1), or discuss the funding opportunities for Country and Regional Nodes (7.4.2).

It is agreed that these two items will be kept as standing items unless the council decides otherwise.

ACTION: Call for Volunteers to join these two interest groups. The formation of the interest groups and the scoping exercise to be reported to ICCAC in May at HVP5.

8. Items for information

8.1 WHO relationship

Helen Robinson reported that involvement with WHO will have implications for members that are working more closely with their Ministries of Health. She will be meeting with WHO in Geneva next month and will have more to report at the Paris meeting.

9. Recommendations to the Scientific Advisory Committee

None

10. Other matters

10.1 HVP5

Draft program has been circulated to the council members. Heather Howard explained the major expenditures for the meeting. She also drew members' attention to several important activities that occur at the meeting:

- Report from the ICCAC Chair at HVP5 on the key activities and achievements of the ICCAC
- Report from each Country Node – to be given at Friday's ICCAC meeting; it was agreed that the ICO would provide an outline/template to assist members in framing these reports; those members not able to attend the meeting in person will be asked to provide written reports in advance of the meeting
- Election of ICCAC Chair – will occur in May at HVP; Nominations close Midnight GMT 19 April 2014

ACTION

- ICO to develop template for the Country Node report and circulate to the council members; report to be sent to ICO by 9 May
- Council members to send ICO their suggestions on the HVP5 program by 11 Apr 2014

11. Next Meeting

23 May – Paris, face-to-face

Meeting closed 12:10AM 26th March 2014 Melbourne time.