



sharing data · reducing disease

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MINUTES

International Confederation of Countries Advisory Council
26th November, 2013 - 11:10PM Melbourne, Australia time
Via Calliflower

ATTENDEES

| | |
|------------------------------------|----------|
| Martina Witsch-Baumgartner (Chair) | Austria |
| Zilfalil bin Alwi | Malaysia |
| Augusto Rojas-Martinez | Mexico |
| Tilak Shresta | Nepal |
| Andrew Devereau, Sir John Burn | UK |

ICO:

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

Apologies

| | |
|---------------------------------------|---------------|
| Graham Taylor, John Coghlan | Australia |
| Thomy de Ravel, Helene Antoine-Poirel | Belgium |
| MilanMacek | CzechRepublic |
| Ming Qi | China |
| Andreas Hadjisavvas, Maria Loizidou | Cyprus |
| Sherifa Ahmed Hamed | Egypt |
| Mahmoud RaafatKandil | Egypt |
| MakiaMarafie, Fahd Al Mulla | Kuwait |
| Amir Feisal Merican | Malaysia |
| Luis Figuera-Villanueva | Mexico |
| Rebati Man Shreshta | Nepal |
| Oyekanmi Nash | Nigeria |
| Hadiza Mahey Rasheed-Jada | Nigeria |
| 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 |
| ChíDũng Vữ | Vietnam |
| Timothy Smith | ICO |
| Helen Robinson | ICO |

AGENDA:

Meeting Opened 11:10PM 26 November 2013 Melbourne time

1. **Welcome**
2. **Apologies**
3. **Welcome new Members**

ICCAC welcomed Nigeria as a formal HVP Country Node.

4. Confirmation of minutes of previous meeting – 17th September, 2013

The minutes were approved without modification.

5. Issues arising from previous meeting

Note that all issues arising from the previous meeting have been taken up in the items below.

6. Country Node activities

6.1 Country Node reports

Austria: Human Genetics Society meeting was held at the end of September and decided to establish a network between the institutes to assist in developing databases in the country. Some new sequencing technologies have been used for routine diagnostic work. It is hoped to obtain some funding support to further develop the node.

Malaysia: HVP South East Asia Regional Node (SEA Node) was launched early Nov. The SEA Node, including Malaysia, Brunei, Vietnam, Singapore and Thailand, agreed to share resources and assist each other in the development of HVP Node. The Asia Pacific Conference of Human Genetics will be held in Hanoi, Vietnam in Dec 2014. The meetings will be held each year in different countries. Malaysia received some funding support from the government which enabled to sustain the Country Node for three years and also provide the secretary service for the SEA Node for two years.

Mexico: A workshop was held with bioinformaticists. A meeting was also held with colleagues to discuss about utilizing databases. There are challenges to collect data from patients. Committees were set up to develop the Mexico Node.

Nepal: Arrangement is been made to send a student to Malaysia for training.

UK: Sir John Burn is now the Vice Chair of the British Society of Genetics Medicine and will promote to set up a formal relationship between the Society and HVP. The Society may also assist in managing the node. Relevant database tools are at the final stage of development. Discussions were taken place about making some UK data available for the InSight database. Approaches were explored to make data more accessible in unidentified way. Workshops were organized for the development of clinical databases. Guidelines are also in development.

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

Three countries, South Africa, Italy, and Democratic Republic of the Congo, have indicated to ICO their intention to join HVP as Country Node. Application form for interim Country Node was sent to the representatives in these countries. There are several more countries have also expressed interest in starting a node, including Brazil, Portugal, India, Nigeria, Philippine, Singapore, Sri Lanka.

Prof Cotton reported his recent trip to Japan to attend the meeting of Japanese Society of Human Genetics and his discussion with Japanese genetists and informaticist about setting up Japan Node.

Sir John Burn (together with Casimiro from UNESCO and Vera Lopes from Brazil) reported the World Science Forum they were attending and connections with Argentina and some South American countries. HVP and idea of data sharing were well promoted at the meeting.

6.3 HVP Country Node Baseline Report: update on progress

The links to the country database and the guide were forwarded to the members. The database serves two purposes: track activity in Genetics and Genomics at the country level and provide a space where we can start collecting examples of policies and procedures for other countries and Country Nodes to use as models. The completed surveys received by ICO have been uploaded to the database. Over the next month, ICO will add other

relevant documents, eg. presentations at the workshops and conferences. ICO plans to make the database publicly accessible from 1st Jan 2014.

The guide will be further developed to a Solution Blueprint - a document that will capture all information on HVP Country Nodes and databases as well as how to operate them. ICO will keep working on the document over the next month. It will also go live from 1st Jan 2014. It will state that the information was approved by the ICCAC. Input and feedback from the members are required.

ACTION:

- **ICCAC members to provide comments/feedback to the country database and the guide document. Comments on the databases can be submitted to Tim Smith (tim@variome.org). Comments on the guide can be submitted online using the comment box at the bottom of each page.**
- **ICCAC members to forward any relevant document, presentations and reports that might be useful to Tim Smith.**

6.4 Guidelines for Country Node formation

The council approved final version of the document on definition, role, types of HVP Country Node and proposed procedures to become a Country Node. The new procedures for establishing HVP Country Nodes will be effective from 1 January 2014.

7. Working towards 2016 HVP Roadmap

7.1 Roadmap summary and role of ICCAC: Discussion of attached action summary

This is an ongoing discussion. ICO hopes that the council works out how ICCAC can assist with achieving the goals defined in the HVP roadmap 2016, especially when it is about a half way through the roadmap term. It was suggested that the ICCAC members to fill the role of ICCAC in the document.

ACTION:

- **ICCAC members to fill the column of "role of ICCAC" in the document before the next council meeting.**

7.2 Standards Development Process/Activity Proposals

None

Members discussed what standards should be developed. It was agreed that standards for database and minimal requirements for Country Node should be developed. In addition, Augusto raised the possibility to create a certification system of the genetic/molecular tests performed in developing countries. The idea was that this system would help laboratories to warranty the quality of the tests and the national health systems as well as contribute the QA efforts of the HVP data.

7.3 Working Groups under the purview of the Council

None

7.4 Interest groups

None

8. Items for information

8.1 ISAC election

Heather Howard informed the ISAC election progress. There will be six ISAC members elected by ICCAC and another six by Gene and Disease Database Council. Nomination was completed. Voting form will be distributed soon. Voting will be held on 1 – 5 December 2013, with election results announced to HVP Consortium Members on 9 December 2013.

9. Recommendations to the Scientific Advisory Committee

None

10. Other matters

None

11. Next Meetings - all via Calliflower unless otherwise indicated

- 4 February 2014
- 25 March 2014
- 23 May - face to face, Paris

Meeting closed 12:10AM 27th September 2013 Melbourne time