



sharing data · reducing disease
an NGO Official Partner of UNESCO

MINUTES

International Confederation of Countries Advisory Council
3 February 2015 1200hrs GMT/UTC

MEMBERS

Present

Interim Members

Zilfalil bin Alwi (Deputy Chair)
Matthew Lebo
Domenico Coviello
Tilak Shrestha
Peter Taschner
Marielle E van Gijn
Hadiza Mahey Rasheed-Jada
Johan Rung
Sir John Burn

Malaysia
Canada
Italy
Nepal
Netherlands
Netherlands
Nigeria
Sweden
UK

Observers:

Peter Pearson

Brazil

Invited Attendees:

Rosemary Ekong
Raj Ramesar

Nigeria
South Africa

ICO Staff:

Heather Howard (Operations Manager)
Helen Robinson (HVPI Liaison – WHO)
Timothy Smith (Communications Officer)

Apologies

Interim Members

Graham Taylor
Martina Witsch-Baumgartner (Chair)
Thomy de Ravel
Kathleen Claes
Jordan Lerner-Ellis
Ming Qi
Andreas Hadjisavvas
Maria Loizidou
Milan Macek
Sherifa Ahmed Hamed
Mahmoud Raafat Kandil
Maurizio Genuardi
Makia Marafie
Amir Feisal Merican
Augusto Rojas-Martinez
Luis Figuera-Villanueva
Rebati Man Shrestha
Oyekanmi Nash
Myungchull Rhee
Jong Bhak
Angel Carracedo
Maria Jesus Sobrido
Richard Rosenquist
Andrew Devereau
Mike Watson
Bruce Korf
Aída Falcón de Vargas
Chí Dǔng Vǔ

Australia
Austria
Belgium
Belgium
Canada
China
Cyprus
Cyprus
Czech Republic
Egypt
Egypt
Italy
Kuwait
Malaysia
Mexico
Mexico
Nepal
Nigeria
South Korea
South Korea
Spain
Spain
Sweden
UK
USA
USA
Venezuela
Vietnam

Observers:

Denise Brito
Celeste Bento

Mozambique
Portugal

Invited Attendees:

Vera Lopes

Brazil

1. Welcome

2. Apologies

Apologies were noted as above.

3. Welcome new members

Canada (represented by Jordan Lerner-Ellis and Matthew Lebo) has transitioned to Interim Status.

4. Confirmation of minutes of previous meeting

Minutes were confirmed unanimously.

5. Matters arising from the previous meeting

All matters taken up in the items below.

6. Horizon 2020 Project – Maurizio Genuardi

Domenico Coviello provided a report on behalf of Maurizio Genuardi of the discussions between interested members of the Council since the last meeting. The call for applications that was being considered was deemed not to be suitable for an application. However, due to the level of interest amongst Council members to share data and link genotypic clinical data, and the amount of work that has already gone into preparing background material for an application, Domenico Coviello and Maurizio Genuardi undertook to look for additional calls being released through the Horizon2020 framework, or similar programs, on an ongoing basis. Peter Pearson commented that what HVP Country Nodes are trying to achieve is clearly a sub-component of the aims of the entire Horizon2020 Framework, however that sub-component is a very small part of the larger program and risked being overlooked, therefore it was right not to continue with the application.

Helen Robinson suggested that the Council ask Thomy de Ravel to visit Diana Salmen at the European Commission to discuss other possibilities.

7. Country Node Development – Helen Robinson

Discussion on this item followed on from the discussions held late last year regarding how the ICCAC can oversee the development and strengthening of HVP Country Nodes during 2015 and the various strategies for achieving this outcome.

Two draft documents were circulated for comment:

1. A set of PowerPoint slides that cover material about the establishment and operation of HVP Country Nodes
2. A draft matrix that sets out five stages of Node development and four dimensions of Node activities

On the basis of comments received so far, three actions were agreed:

A Development of a Practical guide for establishing and operating an HVP Country Node

The slides can form the basis for preparing a practical, web-based guide to be made available on the new website. A draft guide will be developed by the ICO for members to comment on it before it is placed on the website.

B Up-dating information about each current node on HVP website

Members were asked to review the material [currently on the HVP website](#) to check the details about their Node and provide their advice as both the minimum information that should be available for every Node and the desirable information that should be made available in the near future.

It was agreed that:

1. the **minimum information** on the HVP website for each HVP Country Node with Interim Status should be:
 - a. a contact email address that is checked at least once a week
 - b. Name, title, institution and telephone number of person who represents the HVP Country Node
 - c. Contact details and links to National Society for Human Genetics and Genomics
2. **Additional** information if available should include:
 - a. Contact details of other key people involved in the Country Node
 - b. The types of variant data that are of interest to the node at the current time
 - c. Details of the planned meeting/s of Country Node for 2015

3. Those Countries with **Observer status** only should refer to details of that observer – name and email address only
The ICO will work with members to assist in providing this information in a timely fashion.

C Introduction of an Award/series of Awards recognizing progress in Node activities

Members agreed that establishing an award system for HVP Country Nodes should be developed for their consideration at the next meeting. Several principles were put forward to guide the ICO in preparing a draft:

1. That the aim should be to present the award/s at HVP6 at UNESCO in 2016
2. The award should be free registration at HVP6 and a program slot to present to the plenary group the progress made by the Country Node
3. That Nodes would need to apply in order to be considered for an award, that is, it should be voluntary
4. The 5X4 matrix should form the basis for establishing progress but the essential feature was the contribution made by the Country Node to advancing the cause of HVP in general.

8. **Global Globin Initiative – Zilfalil bin Alwi**

Zilfalil bin Alwi reported to the Council the progress of the group convened to establish the GGI. Over the past few months several teleconferences have taken place and a draft document outlining the project is being prepared. This will be shared with the Council for comment when a draft is complete. Contact has been made with the Gates Foundation with a view to seeking funding for the Project. The initial planning meeting slated for Leiden in April has been postponed to allow more time for the project details to be fleshed out. The GGI will be discussed at the Human Variome Project session of the upcoming HUGO Human Genome Meeting in Kuala Lumpur on the 17th of March. Speakers at this session will be Helen Robinson, Raj Ramesar, Ming Qi, Andreas Hadjisavvas, and Zilfalil bin Alwi.

Helen Robinson reminded the Council that the core of the GGI is to strengthen HVP Country Nodes by using the haemoglobinopathies as an entry point to help as many countries as possible build their capacity in genomic medicine. Through tackling issues associated with generating variant data on the haemoglobinopathies and sharing it with existing international databases, the GGI will develop solutions for each involved country that will be generalizable to other genetic disorders.

9. **BRCA Challenge – Sir John Burn**

Sir John Burn reported that it is looking likely that funding will be forthcoming from AstraZeneca to support the work of the ENIGMA group to form the basis of the interpretation committee of the BRCA Challenge. He also reported that he is seeking additional funding for administrative and scientific support to create country-specific collections of whole genome data, possibly at EBI. These collections could form the basis of HVP Country Nodes. The BRCA Challenge is working with the Data Working Group of the Global Alliance for Genomics and Health to create an API for extracting BRCA data from whole genome datasets. AstraZeneca are also providing funds for a meeting of the BRCA Challenge at UNESCO in June 2015. This meeting will bring together the current BRCA Challenge Steering Committee with other relevant international experts. It is one of the major means of the Human Variome Project providing support to the Global Alliance.

10. **Recommendations to the Scientific Advisory Committee**

No recommendations were proposed.

11. **HVP Country Node Progress Updates**

Peter Pearson reported that a molecular genetics meeting will be held in Brazil in June 2015. He further reported that the Global Alliance for Genomics and Health will be represented at this meeting. He has suggested to the Global Alliance that they should assist in efforts to obtain funds for the development of an HVP Country Node in Brazil.

Domenico Coviello reported that the HVP Italian Node is considering 2015 a pilot phase and work has begun with four laboratories. These laboratories are pooling their data using LOVD. Progress will be reported at the Italian Society meeting in October. It is hoped that this will encourage more laboratories to participate.

12. Other matters

No other matters were discussed.

13. Next Meetings

- Tuesday 7 April 2015 1200hrs GMT/UTC
- Tuesday 2 June 2015 1200hrs GMT/UTC