THE HUMAN VARIOME PROJECT

sharing data · reducing disease

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MINUTES

International Confederation of Countries Advisory Council
17th September, 2013 - 10:10PM Melbourne, Australia time
Via Calliflower

ATTENDEES

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

AGENDA:

Meeting Opened 10:10PM Melbourne time

1. **Welcome**

2. **Apologies**

3. **Welcome new Members**

    ICCAC welcomed South Korea as a formal HVP Country Node.

4. **Confirmation of minutes of previous meeting – 6th June, 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

This item was skipped in this meeting owing to time constraints. Country Node representatives will give report in the next council meeting.

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. ICO is waiting for their reply.

There are several more countries have also expressed interest in starting a node, including Brazil, Portugal, India, Nigeria, Philippines, Singapore, Sri Lanka. They are currently undertaking discussions with ICO regarding formation of their respective Country Nodes.

6.3 HVP Country Node Baseline Report: update on progress

It was proposed at the last council meeting that the ICO would create a simple electronic database with compiled information on each country undertaking some form of genetic testing, irrespective of their current formal association with HVP.

ICO is in the process of establishing the country database. It contains relevant general and health information over 150 countries (links to WHO country health information and Global Health Observatory, World Bank and OECD databases), reports and publications of nationally based testing and data collection and sharing, as well as information on HVP Country Node status. ICO will forward members an electronic link to view this before the next meeting so it can be discussed at the next council meeting. It is hoped that this will be fully functional for 2014 and will assist in preparing the report on Country Node activities due for completion by the ICACC at the end of 2014.

> **ACTION:**
> - **ICO to share the link to the country database and seek feedback from the council members**

6.4 Guidelines for Country Node formation: discussion of attached two draft papers:

1   A new definition for a HVP Country Node and the process for formal establishment, and

2   Guide to assist in establishing an HVP Country Node

Helen Robinson explained that the drafts had been developed in response to the request at the last council meeting, when members asked the ICO to develop a model for their consideration that would include different types of national membership of ICCAC and suggested terms like observer, interim and full node. She drew members attention to the implications of these changes and shared the written feedback the ICO had already received regarding the draft, particularly in relation to the extent to which the data collected and stored had to meet clinical standards. Following a lively discussion, it was decided to produce a further draft with the following changes:

a.   That the requirement for a single repository was too prescriptive, and that more emphasis should be given to the possibility of a country nodes being "federated" databases or networked repositories that store and share data generated within the country; this broader definition would give more emphasis to the ability to collect, store, identify and share information on variation in the human genome that has been generated

within the country through a variety of mechanisms, including research activities, clinical practice or other similar means;

b. Indicating that while clinical quality data was the overall goal for collection, storage and sharing within each country, it was not practical to impose this on many countries in the immediate future; rather countries would need to commit to this goal for the longer term and more importantly, that the quality of the data would need to be assessed in some agreed manner, and that this process would result in the stored information being flagged against agreed HVP standards that would allow for international recognition of these data quality standards.

It was also agreed that the process for setting standards of data quality will be put on the agenda for the ICCAC meeting in Paris in May 2014. A new draft of the two documents will be circulated for comment prior to the next meeting. The ICO will endeavour to obtain feedback from as many ICCAC members as possible. Comments will be complied so that a penultimate draft can be approved at the November meeting. Given the implications of these changes, comments will also be sought from the ISAC at their next meeting. It was hoped that the new documents can be finalised by the end of the year so that the new processes would be fully implemented in 2014.

> **ACTION:**
> *   **ICO to make amendments and send a new draft paper for their feedback before the next meeting**

7. Working towards 2016 HVP Roadmap

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

Linked to the discussion above in Item 6.4, it was suggested that assessing the quality of data collected and stored and related standard development should be taken up in more detail when determining the future work plan for ICCAC. This is scheduled as part of the review of activities necessary for up-dating the HVP Roadmap for the period 2014-16 at the face-to-face meeting in Paris in May 2014.

Graham Taylor indicated that he will be discussing these important issues in his scheduled session on VCF files at ASHG, Boston in October 2013. He encouraged anyone interested in these particular issues to contact him directly.

8. Items for information

8.1 Up-date on World Health Organization (WHO) consultation

Helen Robinson informed that the WHO had recently agreed to establish a global human genomics and public health program as part of its program budget for 2014-2015. The new program will be part of Health Systems and linked to innovation in primary health care service delivery and patient centred care, rather than being a disease-focussed program. The details of work plan for the program and its priorities are still under discussion, and HVP is involved in this process. Until more of these details are worked out, a public announcement is premature. However, the agreement to establish the program will be mentioned at the World Health Summit in Berlin on 20 October 2013 during a session on genomics and public health challenges in developing countries at which both WHO and HVP are speaking. A more formal announcement is planned for April 2014 to coincide with a joint HVP/HUGO session in Geneva where the headquarters of WHO is based.

9. Recommendations to the Scientific Advisory Committee

None

10. Other matters

10.1 ISAC election

Heather Howard explained the ISAC election procedures. There will be six ISAC members elected by ICCAC and another six by Gene and Disease Database Council. Call for nomination for ISAC is open until 31 October 2013. Each nomination should be made by a minimum of two HVP Consortium members. Biographical information and position statements of nominated candidates will be presented to the Council members by 15 November 2013. Voting will be held on 1 – 5 December 2013, with election results announced to HVP Consortium Members on 9 December 2013.

10.2 HVP5

Heather Howard talked about the HVP5 organisation. There will be an Africa satellite meeting on the first day (Monday). Meetings of working groups and interest groups can also be held on this day. Please inform ICO if members plan to hold meetings. The next three days (Tuesday to Thursday) are for submitted abstract sessions. The call for abstracts has already gone out. Members are encouraged to respond. The fifth day (Friday) is for ISAC and council meetings.

> **ACTION:**
> - **ICO to inform members the HVP5 program, once it is finalised**
> - **Council members to inform ICO if they plan to hold working group or interest group meetings on the first day of HVP5**
> - **Council members to consider abstracts to be submitted for HVP5**

10.3 Progress on formation of South Asia Regional Node

Zifalil bin Alwi introduced the latest progress in Malaysia node. He particularly informed the council the progress on formation of South East Asia (SEA) Regional Node based in Malaysia. The SEA Regional Node has received funding support from Malaysia government. It has been planned that the Node will be launched in October 2013.

> **ACTION:**
> - **Malaysia Node and ICO to coordinate the arrangement for the launch of South Asia Regional Node**

11. Next Meetings - all via Calliflower unless otherwise indicated

- o 26 November 2013

- o 28 January 2014

Meeting closed 11:25PM Melbourne time