



sharing data · reducing disease
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MINUTES

International Confederation of Countries Advisory Council
5 Aug, 2014 – 10:00PM Melbourne, Australia time
Via Calliflower

ATTENDEES

Graham Taylor	Australia	Apologies	
Martina Witsch-Baumgartner (Chair)	Austria	Thomy de Ravel	Belgium
Kathleen Claes	Belgium	MilanMacek	Czech Republic
Ming Qi	China	Andreas Hadjisavvas, Maria Loizidou	Cyprus
Domenico Coviello	Italy	Sherifa Ahmed Hamed	Egypt
Augusto Rojas-Martinez	Mexico	Mahmoud Raafat Kandil	Egypt
Mike Watson	USA	Maurizio Genuardi	Italy
Observers:		Myungchull RHEE, Jong Bhak	South Korea
Peter Taschner	Netherlands	Makia Marafie	Kuwait
ICO:		Zilfalil bin Alwi, Amir Feisal Merican	Malaysia
Richard Cotton (HVP Scientific Director)		Luis Figuera-Villanueva	Mexico
Heather Howard (HVPI Operations Manager)		Tilak Shrestha, Rebati Man Shrestha	Nepal
Helen Robinson (HVPI Liaison – WHO)		Oyekanmi Nash	Nigeria
Timothy Smith (HVPI communications Officer)		Hadiza Mahey Rasheed-Jada	Nigeria
Fan Li (Liaison Officer)		Angel Carracedo, Maria Jesus Sobrido	Spain
Invited Attendees:		Andrew Devereau, Sir John Burn	UK
Raj Ramesar	South Africa	Bruce Korf	USA
Rosemary Ekong	Nigeria	Aída Falcón de Vargas	Venezuela
Peter Pearson	Brazil	Chí Dũng Vŭ	Vietnam
		Celeste Benta	Portugal

AGENDA

1. Welcome

2. Apologies

See list above.

3. Welcome new Members

ICCAC welcomes Peter Taschner from Netherlands and Celeste Bento from Portugal to formally become ICCAC Observers.

4. Confirmation of minutes of previous meeting – 23 May, 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. Horizon 2020 project

It was agreed at the last council meeting that a multi-country application for an EC Horizon 2020 grant would be developed. Martina developed a preliminary proposal outline for discussion (under PHC-30-2015: Digital representation of health data to improve disease diagnosis and treatment) and asked all interested countries to fill in more information. Everyone with relevant experience is encouraged to contribute as much as possible. The grant application deadline is April 2015.

Briefly, the council agreed to focus on the development of following components of the grant application (Please see Martina's summary for details):

- A clear overall plan
- Defined work packages to target difference issues: eg. genotype and phenotype database linked to clinical information; infrastructure to be developed at local level, especially in developing countries; coordination within each country, accessing and sharing data internationally, etc.
- Identify the partners who are most suitable for each of the agreed work packages
- Defined roles and tasks of each partner to be included in the application

ACTION

- Martina to prepare a summary of the key points of this discussion and the steps forward from now on
- Martina to contact with Mireille Claustres who may be willing to assist in preparing and co-ordination of the grant application
- Each interested country representative who proposes to be part of the application will need to begin to provide all the relevant information for their country in the relevant place of the application pack in time for the next meeting.

7. Global Haemoglobinopathies Initiative

Helen drew members attention to the three documents provided as part of this agenda item. There was a short review of the progress made with regard to the initiative so far. Mexico, China and Malaysia had provided considerable information regarding the situation in their respective countries. Following discussion it was agreed that the group will focus on all haemoglobinopathies, related thalassaemias, and sickle cell disease together, rather than separately, knowing that each country faced different disease challenges. A working definition will need to be developed and agreed to. It was also agreed that while most ICACC members would have an interest in collecting and sharing data related to these genes and variants, not all members would be able to devote time to the project. Consequently it was decided to establish a smaller sub-set of ICACC members to work on this project. Other non-ICACC members would be co-opted to this group as required. The group will be co-ordinated by ICO for the next few months, until a more suitable person could be identified. This would enable the initiative to progress as quickly as possible. It was noted that Prof. Sir David Weatherall had agreed to participate in the initiative and had made several suggestions of other partners to approach. Prof. Cotton had also had a series of useful meetings with key people while he was in Oxford/UK. It is hoped to work towards an international meeting in the first half of 2015. Raj drew attention to the H3Africa meeting in November 2014 and so it was agreed to try to make as much progress as possible before this meeting on

- the precise coverage of the initiative,
- determining data formats for international consistency
- reviewing data collection policies that may be used,
- agreed nomenclature to be used by all partners,
- identifying existing national sources of data.

Ming introduced a new project on thalassaemia initiated in China, funded by BGI. The project aims to collect data generated by NGS from 20,000 cases across 5 provinces in China. It also plans to collect data from 1,000 Sickle Cell Anemia cases in African countries. The details of this project will be shared with the Haemoglobinopathies group.

ACTION

- ICO to organize separate meetings and work plan for this initiative
- Haemoglobinopathies Initiative group will provide a regular report to ICCAC at each meeting

8. Working towards 2016 HVP roadmap - role of ICCAC

This item was skipped due to time restriction.

9. Country node updates

This item was skipped due to time restriction.

10. Recommendations to the Scientific Advisory Committee

None

11. Items for information

11.1 WHO relationship – this item was deferred to the next meeting owing to lack of time for discussion.

12. Other matters

None

13. Next Meetings - all via Calliflower unless otherwise indicated

- 23 Sep
- 2 Dec

Meeting closed 11:30PM 5 Aug 2014 Melbourne time.