



sharing data · reducing disease
an NGO Official Partner of UNESCO

MINUTES

International Confederation of Countries Advisory Council
7 April 2015 1200hrs GMT/UTC

MEMBERS

Present

Interim Members

Matthew Lebo	Canada
Domenico Coviello	Italy
Maurizio Genuardi	Italy
Augusto Rojas-Martinez	Mexico
Peter Taschner	Netherlands
Marielle E van Gijn	Netherlands
Sir John Burn	UK
Mike Watson	USA
Raj Ramesar	South Africa

Observers

Denise Brito	Mozambique
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ICO

Helen Robinson (HVPI Liaison – WHO)
Timothy Smith (Communications Officer)

Apologies

Interim Members

Graham Taylor	Australia
Martina Witsch-Baumgartner (Chair)	Austria
Thomy de Ravel	Belgium
Kathleen Claes	Belgium
Jordan Lerner-Ellis	Canada
Ming Qi	China
Andreas Hadjisavvas	Cyprus
Maria Loizidou	Cyprus
Milan Macek	Czech Republic
Sherifa Ahmed Hamed	Egypt
Mahmoud Raafat Kandil	Egypt
Makia Marafie	Kuwait
Zilfalil bin Alwi	Malaysia
Amir Feisal Merican	Malaysia
Luis Figuera-Villanueva	Mexico
Tilak Shrestha	Nepal
Rebati Man Shrestha	Nepal
Oyekanmi Nash	Nigeria
Hadiza Mahey Rasheed-Jada	Nigeria
Myungchull Rhee	South Korea
Jong Bhak	South Korea
Angel Carracedo	Spain
Maria Jesus Sobrido	Spain
Richard Rosenquist	Sweden
Johan Rung	Sweden
Andrew Devereau	UK
Bruce Korf	USA
Aída Falcón de Vargas	Venezuela
Chí Dũng Vũ	Vietnam

Observers

Peter Pearson	Brazil
Celeste Bento	Portugal

Invited Attendees:

Rosemary Ekong	Nigeria
Vera Lopes	Brazil

ICO

Heather Howard (Operations Manager)

1. Welcome

In the absence of Martina Witsch-Baumgartner, Peter Taschner chaired the meeting.

2. Apologies

Apologies were noted as above

3. Confirmation of minutes of previous meeting

The minutes of the previous meeting were confirmed unanimously.

4. Matters arising from the previous meeting

All matters taken up in the items below.

5. Horizon 2020 Project – Maurizio Genuardi

Maurizio Genuardi reported that he has had contact with his university's office in Brussels. All researchers from his university that had previously applied for or shown interest in EU projects were contacted and provided with guidance about the Horizon2020 project. According to this guidance, there is still some room for making changes or additions, for example, increasing the specificity of items within project proposals. Maurizio and a collaborator have proposed a project looking at big data and correlation with phenotypes. Maurizio is expecting his university's office to contact him shortly regarding next steps.

Domenico Coviello reported that he was contacted by the office in Brussels for the Ligurian region and alerted to an individual from Spain who was searching for partners in the call that was floated for a Human Variome Project application. Upon contacting the individual he was informed that partners had already been found, but Domenico undertook to keep in contact with the Ligurian office in Brussels. Maurizio Genuardi suggested that Council members monitor the Horizon2020 website for further partnership calls.

Helen Robinson suggested that framing a proposal irrespective of the deadlines and formalities would be a useful exercise to try and work out more clearly exactly what various groups or sub groups might need to do. Maurizio undertook to draft a proposal 'backbone.'

ACTION: Maurizio Genuardi to draft a proposal 'backbone' that scopes out a potential project between HVP Country Nodes.
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6. Proposal for Award for Progress for HVP Country Nodes 2016

Helen Robinson reminded the Council that she was tasked with preparing a proposal for a scheme for assessing and rewarding progress by HVP Country Nodes. Helen Robinson presented the attached proposal including a process, timeline and application form.

Domenico Coviello asked for a clarification of the definition of progress. Helen Robinson responded that the intention was to be flexible with the definition, know that many of the Nodes are at different points in their development and are all rather unique in the way they respond to their own local contexts. Those judging these awards will need to be aware of this, and as such, a telephone interview was proposed as part of the process, to allow the applicants to talk more freely and openly to the selection committee about what they think their progress has been, and thus, better enable the selection committee to make comparisons between Nodes that are very different. The proposed application form also gives the applicants the opportunity to note any specific barriers to their progress that they feel have had a direct impact on their progress and that should be taken into account. Peter Taschner suggested that the applicants should also list as part of the application, any solutions to these barriers that they implemented.

Helen Robinson undertook to make the suggested changes to the proposal and then forward it to the International Scientific Advisory Committee for comment before presenting it to the Council again.

ACTION: Helen Robinson to present updated proposal to the International Scientific Advisory Committee for comment.

7. Up-dating information of HVP Web site for HVP Country Nodes – Helen Robinson

Helen Robinson thanked those members who had responded to the ICO's request for information and asked those who had yet to respond to do so. She advised the Council that the website would be updated with the new information in the coming weeks.

8. HVP Country Node Guide

Helen Robison reported that the draft guide for HVP Country Node Development will be circulated for comment at the next meeting of the Council. Helen Robinson asked if there were any particular areas that members would like additional guidance. Council members requested additional guidance on minimum content requirements. Peter Taschner reminded the Council that an HVP Working Group is looking into this for Gene/Disease Specific Database and this work will inform what is required for HVP Country Nodes.

Members also requested guidance on the technical systems available for operating databases and that it include whether they allow data to be stored within the country or require data to be held elsewhere. The Council discussed the benefits for both options. John Burn reported on progress with EBI offer for hosting country specific data.

9. Global Globin 2020 – Zilfalil bin Alwi

Helen Robinson reported on the Global Globin 2020 initiative in the absence of Zilfalil bin. A very successful meeting was held during the HUGO HGM meeting on the 17th March. The members of the GG2020 steering group agreed to a governance structure with Zilfalil bin Alwi and Raj Ramesar to lead it. The steering group are now finalizing a paper describing the project. Cyprus has agreed to be a model for the Project finding partners with Thalassaemia International Federation, WHO and UNESCO. The project will cover various types of thalassaemias, because they are the most organised and the most progress can be made the most quickly. Sickle cell diseases will take more time but will follow the model developed for the thalassaemias. The initiative will eventually expand to include G6PD. The steering group is finalising a database of the initiative members detailing those who want to be on the steering group and those who want to be involved. The next step is to find some money to hold a meeting. Progress on this front has been good and the steering group hope to run such a meeting by the end of the year.

10. BRCA Challenge – John Burn

John Burn reminded the Council of the upcoming BRCA Challenge meeting in June and stated that the BRCA Challenge Steering Committee were very keen to get as broad a geographic representation as possible to the meeting. He also mentioned that while the focus of the meeting was obviously on the BRCA1 & 2 genes, that the BRCA Challenge is being run as a model for other diseases and the meeting will discuss information that is of benefit to those interested in other areas.

11. Recommendations to the Scientific Advisory Committee

The Council requested that the ICO provide the ISAC with a copy of the proposal for Awards for Progress for HVP Country Nodes 2016 and request comments on the proposal (see Item 6).

12. HVP Country Node Progress Updates

John Burn reported that he had been made Chair of the UK's Rare Disease Registries and Genetic Databases Advisory Group. This group is in the final stages of gaining clearance to use the UK national cancer registry systems for rare diseases. This would give them statutory powers to extract information from medical records to create up to 6,500 rare disease registries. These would start with inherited breast cancer and the mismatch repair genes, but ultimately would expand to all rare diseases. John Burn further noted that the software systems used to create these registries would be made available.

Domenico Coviello reported that at a recent meeting of the Board of the Italian Society of Human Genetics a decision was made between the Italian Country Node and a national group working on exome data to join forces establish a national database in Bologna.

13. Other matters

No other matters.

14. Next Meetings

- Tuesday 2 June 2015 1200hrs GMT/UTC

ICCAC – Agenda Item – draft Award for HVP Country Node

At the last ICCAC meeting it was decided to investigate the feasibility of establishing an Award for HVP Country Nodes in recognition of their progress. This paper provides a draft for discussion:

1 Process and Timelines - Applications and Selection

KEY MILESTONES	ROLES & RESPONSIBILITIES	DATE
Consult and agree on awards process	ISAC agrees ICCAC recommendation : – application process – selection process	draft to ICCAC – 7 April 2015
Launch Awards	setup web-site circulate application form	1 June 2015
Promote award process	send reminders	September December
Applications close:	agree selection committee members	31 January 2016
Selection/Assessment process	– convene selection committee – review application forms – conduct interviews – decision made	mid-February end-February
Applicants advised of result	Invitation to present	1 March 2016
Awards Ceremony		HVP 6 at UNESCO 30 May 3 June 2016
Round 2?	Evaluate process for review and improve for HVP7 2018	Launch new round – 1 January 2017

APPLICATION PROCESS

- 1 Complete and sign an application form attaching necessary evidence
- 2 Enquires handled by ICO
- 3 Agree to be interviewed by members of Selection Committee

SELECTION PROCESS

- 1 Selection Committee – 5 members: 2 from ISAC, 2 from Gene and Disease ; nominate a Chair from the group
- 2 Review applications virtually and individually
- 3 Short-list for telephone interview
- 4 Final ratings and decision – with Committee written report on their decision
- 5 Selection Committee Chair to host/chair event at HVP6

2 Draft Application form – see attached



AWARDS - 2016
CALL FOR APPLICATIONS
February 2015

HVP supports the growth of viable, sustainable national country nodes across the world. This growing network actively contributes to the achievement of the broader vision of the Human Variome Project by building national capacity for open sharing of data and variant information both nationally and internationally. The sharing supports comprehensive and cost-effective human genetic and genomics services to promote health for all people. With this in mind, the International CCAC has decided to establish an Awards Scheme to recognize outstanding performance of individual HVP Country Nodes.

Four key criteria have been selected as priority areas for assessment of progress in 2016. These are:

1. **Progress on data collection** –this will include assessment of the quality and degree of current data collection given the prevailing circumstances in the country as well as plans to expand data collection and improve the quality of the data identified
2. **Links to stake holders at national level** – this will assess the nodes current links to the various stakeholders at national, regional and international levels, particularly with other HVP Country Nodes, together with plans to improve these links in the next 12 months
3. **Handling of ethical, social and related issues-** this will refer to the Node's activities related to the Node's own assessment of priorities in this area, why they are important, and the activities being both undertaken and planning to be undertaken to address these issues adequately
4. **Plans for future** – an assessment of the future plans of the Country Node and the likelihood of achieving them

While these four key criteria are important, an overall assessment of the Country Node will also be taken into account. Application should focus primarily on activities undertaken during the calendar year 2015, however, any concrete plans scheduled for 2016 can also be part of the application.

Selection process

A panel comprised of five members drawn from the membership of HVP, the International Scientific Advisory Committee (ISAC) and the Gene and Disease Council will form a selection committee. The membership of the Selection Committee will be determined by the ISAC.

There will be a two-step process in assessing progress for the Awards:

1. The degree to which each written application meets the priorities and conditions set out here will be used to determine a short list; and
2. A comparative evaluation of the further information gained in interviewing shortlisted applicants.

The Selection Committee will determine the exact process they will use in determining and evaluating progress. Applications that are brief, focus specifically on the four key criteria, and are supported by clear evidence are likely to be well regarded.

To ensure that there is no conflict of interest, the Selection Committee members will not be involved in any of the individual applications.

The Selection Committee will determine the number of awards to be made.

Eligibility

To be eligible to make an application for the **2016 HVP Country Node Progress Awards**, the application must be made by a current member of the ICCAC and have lodged forms with the HVP International Co-ordinating Office prior to **31 December 2015**.

The Award

Award winner/s will receive:

1. A certificate of commendation; and
2. Free registration for HVP6 at UNESCO in June 2016; and
3. An invitation to make a presentation about their activities at the opening of HVP6 at UNESCO in June 2016

Making an Application

1. Applications must include sponsorship of a member of the ICCAC
2. **Deadline** for applications is midnight **31 January 2016 (GMT)**.
3. Applications should be sent on the appropriate application form and a paper/hard copy or scanned copy sent to the following address:

The Human Variome Project International Office
Level
Carlton South
Victoria 3035
AUSTRALIA

Electronic applications should be sent to the following address:

XXX@variome.org

Any queries or questions of clarification should be sent to the same address.



HVP COUNTRY NODE PROGRESS AWARDS APPLICATION FORM – 2016

INSTRUCTIONS: Please complete the form in the boxes below and answer each question as directly as possible. The Selection Committee will give greater weight to clear and concise responses. Please also add or append any relevant correspondence or documents that would provide direct evidence to the Selection Committee of your activities and progress

APPLICATION DETAILS

COUNTRY:

CONTACT PERSON:

DETAILS OF THOSE INVOLVED IN MAKING THE APPLICATION:

List names and affiliations of those involved in putting this application together

SECTION A Progress on data collection –

this will include assessment of the quality and degree of current data collection given the prevailing circumstances in the country as well as plans to expand data collection and improve the quality of the data identified. Please be succinct and appended any documents that may provide evidence and support to your description.

Please provide details on

- 1) Your current data collection activities in 2015
- 2) Your planned data collection activities in 2016
- 3) An specific barriers that are associated with the situation faced in your country that have a direct impact on your data collection activities and that should be taken into account when assessing your application

SECTION B Links to stake holders at national level –

this will assess the nodes current links to the various stakeholders at national, regional and international levels, particularly with other HVP Country Nodes, together with plans to improve these links in the next 12 months. Please be succinct and appended any documents that may provide evidence and support to your description.

Please provide details on

- 1) Your current activities related to strengthening your ties to various national stakeholders in 2015; refer specifically to any links with other HVP Country Nodes
- 2) Your planned activities to broaden and strengthen links to other key stake holders in 2016
- 3) An specific barriers that are associated with the situation faced in your country that have a direct impact on your activities in this area that should be taken into account when assessing your application

SECTION C Handling of ethical, social and related issues-

this will refer to the Node's activities related to the Node's own assessment of priorities in this area, why they are important, and the activities being both undertaken and planning to be undertaken to address these issues adequately. Please be succinct and appended any documents that may provide evidence and support to your description.

Please provide details on the following

- 1) What are the main ELS issues facing your Country Node currently?
- 2) How did the Node determine these priorities?
- 3) An specific barriers that are associated with the situation faced in your country in relation to ELS issues that have a direct impact on your data collection activities and that should be taken into account when assessing your application

SECTION D Plans for future – an assessment of the future plans of the Country Node and the likelihood of achieving them

Are there any other plans for the Node that have not already been mentioned above that you would like to include? Please provide details below

FURTHER COMMENTS

Please add any further comments here that you would like to add to your application and explain why you have included them.

Application authorization

On behalf of the parties submitting this application, I declare that :

- the information contained in this application is true and correct to the best of my knowledge.
- I agree to be contacted by Selection Committee members to be interviewed should we be short-listed

Signed: _____

Date: _____

Please list any attachments to this application here.