

# Core principles of the working group

- 1. Improve the FAIRness of the IHCC cohorts
- 2. Support open community standards
- 3. Embrace federated paradigm
- 4. Embrace heterogeneity of global cohorts
- 5. Integrate with existing/other cohort networks and platforms
- 6. Support the IHCC scientific agenda
- 7. Determine how to better engage and support LMIC/LRS/LRC cohorts to incorporate their cohort data into the Atlas



#### **Discussing the Challenges**

#### Challenge 2: Harmonized cohort level metadata

Collaborate with other harmonization activities - naturally Maelstrom but potentially other programs (global mental health) that may be more clinical (ICGC/ARGO).

How can we identify existing harmonisation activities and integrate into the work of IHCC data team

Popularise the use of the IHCC model for future cohorts

• e.g. recommended ontologies that are already mapped into the IHCC/GECKO model

Standardised set of cohort data descriptors (e.g. assays, omics types)

Capture this information through surveying cohorts - work with Secretariat

Processes for updating the cohort metadata collected

- How do we keep cohort data updated/refreshed?
- e.g. annual update from cohorts



## **Challenge 3: Cohort access and authorization**

- i) GA4GH standards ie 'passports'
- ii) Working with "team C" to support international data governance/policy development
- iii) Support a pilot access to actual data.
- iv) Implement a package of workshops and tutorials to make the Atlas easily accessible, even for low resource groups, so that its use is massified.
- v) Make the collection of harmonized questionnaires that have been harmonized available in a format that people can directly import in RedCap (and maybe modify from there, trimming down questions, adding new ones, but retaining the GECKO codes for the ones that are in the Atlas already)



## **Expanding the Atlas: Atlas/Cohort Workshop**

- Develop a tutorial/workshop to support individual cohorts for data harmonization and on-boarding into the Atlas
  - Partnership with H3ABionet and Cineca training materials
- Also appetite for more broader dissemination of the Portal.
  - Getting feedback from the cohorts and the research community on utility and data (ie. potential capture of "-omic" data)
- Introduce to GA4GH standards for data and access



#### **Action Items**

- 1. Organise cohort harmonisation workshop for on-boarding into Atlas
  - a. Align with CINECA training materials on GA4GH stds, cohort harmonisation/GECKO model
- 2. Reaching out to the cohorts that make up European 1 Million Genomes
  - a. The project asks each country to provide data from 100k+ participants
- 3. Re-start regular meetings of the WG
  - a. Check the membership list up to date, query cohorts for contacts

## **Attendees - Thank you for your participation!**

- Philip Awadalla
- Thomas Keane
- Hannah Kennel
- Christina Yung
- Melanie Courtot
- Carles Garcia
- Farida Akhtari
- Michael Jones
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- Takayuki Morisaki
- Mamana Mbiyavanga
- Nishadi Rajapakse

- Rongling Li
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- Thomas Keane
- Ricardo Verdugo
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