



# IHCC 5th International Cohort Virtual Summit (ICS5) Executive Summary

*“The journey to globally accelerate science and population health in longitudinal population studies”*

The journey to bring together prospective cohort studies involving at least 100,000 participants to address scientific questions that they couldn't answer alone began in 2015 and continued with the International HundredK+ Cohorts Consortium (IHCC) 5th International Cohorts Summit in 2022.

The four-day virtual summit started out looking back on IHCC's journey over the past year. Day 1 opened with a keynote from Stephen Quake of the Chan Zuckerberg Initiative (CZI) on their commitment to advance research and develop technologies to measure human biology in action over the next 10 years. Following the keynote, we heard from IHCC working groups and pilot projects about their accomplishments in the past year, which included:

- The IHCC Cohorts Atlas expanding to include 70 cohorts representing millions of study participants
- Educational webinars hosted every month, bringing together a wide range of speakers and topics within the IHCC community
- OPICO Pilot project receiving 4-year funding from the French National Cancer Institute to expand beyond the pilot phase
- IHCC Metabolomics Pilot Project publishing their first paper in July 2022
- Two cohorts from Chile and Uganda added as new sites in the IHCC Metabolomics Pilot Project
- IHCC-COVID Mental Health Pilot Project has three publications to date

Furthermore the sessions related to COVID-19 highlighted the impact of the COVID-19 pandemic on mental health, global readiness for future pandemics, and the crucial role IHCC will play in accelerating science for genomics. Each day there were 1-2 roundtables, spurring discussion amongst participants around various topics such as policy tools for starting collaborative projects, polygenic risk scores for predicting disease probability, and cross-cohort exchange opportunities.

In Day 2 opening keynote, Madeleine Thomson from Wellcome Trust addressed the need to understand climate and environmental data, particularly as it relates to population health and cohort science. The following sessions discussed leveling the playing field for cohort success through a 'Cohorts in a Box' concept and leveraging routine health data from virtual cohorts for research. The first panel discussion explored benefits of leveraging the cloud to host cohort data while reducing risk and managing data security concerns. While the second panel highlighted potential collaboration opportunities between industry and IHCC, such as co-development of resources for cohorts.

Day 3 focused on best practices, challenges, and lessons learned from low and middle income countries/low-resourced settings. Dr. Sanjay Juvekar, opened the day encouraging

collaboration, co-creation, and capacity building in low-resource settings. The following sessions discussed the vision of the African Population Cohort Consortium to create a transformational capability and forum on population based cohorts and learnings from the Africa Pathogen Genomics Initiative that can be applied in human genomics. The final two panel discussions explored the opportunities and challenges around data science in Africa and overcoming barriers to cohort science and how IHCC can support cohorts in navigating these barriers.

The final day was a culmination of summit learnings and looking forward to what's next on the agenda for IHCC. Each working group hosted a 45-minute roundtable to discuss summit insights, funding opportunities, collaboration opportunities and next step priorities. Here are some resulting action items from the summit (see attached table for a full list of action items under each working group):

- **Gather** additional financial support for new sites in the Metabolomics Project
- **Explore** the idea of creating international exchange programs with CZI hubs to enhance the skills of the international community
- **Follow up** with all IHCC member cohorts to complete the annual members survey
- **Build** an understanding of climate data within the IHCC membership and rapport with the climate community globally
- **Design** and finalize project planning template for cohort projects + templates for collaboration and data-sharing agreements that are easy to use and fit for purpose
- **Launch** a postdoctoral exchange program for capacity building across IHCC cohorts
- **Develop** ways to share IHCC learnings from the process of creating a federated platform for data sharing with other networks such as the INSPIRE Network
- **Support** APCC with identifying more cohorts in Africa, particularly where there are regional gaps
- **Foster** knowledge sharing between IHCC and APCC in the formative phase (particularly around governance, federated platforms, cohort research)
- **Connect** with the Global Health Network to identify potential opportunities for collaboration

Overall we received great feedback from the summit and we look forward to meeting face-to-face at the next annual IHCC summit (ICS6). Videos of all presentations given during this meeting can be found on the IHCC website here: [Day 1](#), [Day 2](#), [Day 3](#), and [Day 4](#).

268 participants | 43 countries | 20+ cohorts and organizations



## ICS5 Action Items

### **Policies and Systems Working Group (PWG)**

- **Bring** together resources and expertise around how to facilitate data sharing
- **Design** content based on scientific project experiences for a “Starter Pack” around the policy issues. What do you need to know around a project coming together for collaboration
- **Initiate** action teams to tackle specific components of the “Starter Pack” and then come back together to assemble the entire starter pack
- **Learn** and partner with the other working groups to gather lessons learned on the ground with bringing cohorts together. This will ensure the work the PWG group is doing is relevant and specific
- **Develop** the ‘HelpDesk’ to create an open dialogue with all member cohorts to reach out to us for resources and let us know your needs. We can point you to resources if it’s not already available thru a central source
- **Work** with other groups (ex. G2MC policy group) to amplify the work we are trying to do
- **Create** partnerships/projects with ICDA and GBMI (divide and conquer vs. duplicating the same work)
- **Contribute** IHCC Perspective to Global Policy Forum publications

### **Scientific Strategy and Cohorts Enhancement Working Group (SSWG)**

- **Collaborate** with the TWG on mentoring young investigators to seek diverse funding opportunities/exchange programs and how to leverage an organization like IHCC
- **Identify** key thought leaders in IHCC in the relevant fields for scoping (summit presentations: Wellcome Trust, CZI)
- **Develop** strategies on how to react to the funding landscape, look at overlap in interest with Wellcome Trust, CZI. Where can the diverse cohorts in IHCC contribute?
- **Discover** different models for multi cohort funding (ex. disease-specific, similar to Davos Alzheimer's model)
- **Discover** how IHCC can ‘matchmake’ between funding opportunities and cohorts
- **Empower** IHCC members to start projects (bottom-up approach)
- **Create** communities of interested investigators across IHCC based on their shared interests (vaccine response, proteomics, climate science, etc)

### **Data Standards and Infrastructure Working Group (DWG)**

- **Learn** about the principles of multi-cloud from All of Us cohort that can be replicated across different cloud structures
- **Map** back data from secondary resources (GWAS, PGS, etc.) to improve discoverability, show the impact that cohorts are having, and provide abilities to look across the cohorts
- **Discover** opportunities to map into administrative databases (ex. exposure database in Canada)
- **Make** data dictionaries available
- **Look** into data sharing through derived data to demonstrate impact and potentially get past sharing barriers
- **Identify** external funding opportunities to support portal development and inclusion of more cohorts
- **Work** with disease foundations to support pan-cohort activities (success story might come from rare disease)
- **Discover** what is possible between individual and derived data and how can this be done (tiered data sharing by individual cohorts)
- **Examine** linking and standardizing phenotypes and also outcomes (there are phenotype libraries)
- **Link** to groups beyond IHCC (ex. ICDA/GBMI) for reciprocal sharing of knowledge and also representation of data
- **Bundle** cohort-in-a-box to share across cohorts as inclusion in a starter pack - create a checklist for how data can be used and shared
- **Develop** a pilot rare disease “look up” or improve power for under-represented groups/ethnicities

### **Training and Workforce Development Working Group (TWG)**

- **Develop** clear ideas of mentorship and the aims of the different mentorship programs/schemes
- **Draft** IHCC white paper about our training model or about all the IHCC working groups
- **Gather** input and feedback for the Qatar Biobank training modules
- **Consider** how MAUCO program can serve as a springboard to test some ideas of the TWG (cohort exchange, mentorship, etc)
- **Create** a journal club to fill gaps in the seminar schedule to improve the critical skills of junior researchers
- **Identify** people that would like to contribute to training (whether in the journal club or specific techniques)
- **Promote** data analysis skills training partnership Dementia Platform UK(DPUK)/IHCC: How can we promote a training partnership between DPUK and IHCC? With the follow-up aim to develop a face to face meeting at one of the big conferences (ICDA and/or American Society of Human Genomics Meeting)

**Thank you to the sponsors of the IHCC for their generous contribution and continued support of the International Summits!**



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