



International 100K Cohort Consortium

EXECUTIVE SUMMARY

Virtual Summit
Socio / Zoom

May 25th – May 27th, 2021

Hosted by the [Global Genomic Medicine Collaborative \(G2MC\)](https://ihccglobal.org)
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Vision for success:

CREATING A GLOBAL COMMUNITY OF COHORTS,
WORKING TOGETHER TO ADVANCE SCIENCE AND IMPROVE HEALTH FOR ALL.

IHCC Fourth International Cohorts Virtual Summit Executive Summary

In 2015, the National Institutes of Health (NIH) launched an effort to identify all large-scale prospective cohort studies involving at least 100,000 participants to explore the potential of bringing them together to address scientific questions none could answer alone. This effort led to the commission of the Global Genomic Medicine Collaborative (G2MC) to bring together these cohorts through the International HundredK+ Cohort Consortium (IHCC). This group gathered for the First International Cohort Summit in the USA in 2018 followed by a Second Summit in Iceland in 2019. The Third and Fourth International Cohorts Summit (ICS3, ICS4) took place virtually in 2020 and 2021 due to the COVID-19 pandemic.

On day one of the three-day Summit, ICS4, opened with a keynote from Cori Bargmann of the Chan Zuckerberg Initiative on “Accelerating Science Through Technology and Collaboration.” The session that followed was focused on IHCC activities that took place over the last year. Presenters gave updates on six IHCC-funded pilot projects that were awarded and initiated in 2020 - three of which were focused on COVID-19, as well as ongoing projects with the Davos Alzheimer’s Collaborative (DAC) and use of polygenic risk scores (PRS) with cross-cohort data. IHCC’s working groups (WG) (Data Interoperability and Infrastructure, Scientific Strategy and Cohorts Enhancements, Policy and Systems, Learning and Sharing) also gave updates on their recent activities.

Day two began with a keynote from Mary De Silva of the Wellcome Trust on a “Vision to the Future – Disruption in Population Health,” followed by updates from various IHCC members on IHCC’s Strategic Planning initiative. The Strategic Planning activities in 2020-2021 led to a revised Mission, Vision, and Core Values. These were propagated to the WGs to re-evaluate their group goals. Each WG participated in breakout sessions with IHCC members to brainstorm action plans for implementation of the Strategic Plan, the results of which were reported out to all attendees after the breakout sessions. Day two closed with a panel discussion on the challenges of large-scale population cohorts in low resource settings (LRS) and ways that IHCC can support advancement of LRS research and collaboration.

The final day of the Summit hosted keynotes from Ambroise Wonkam of the University of Cape Town on “Why We Should Invest in African Genomic Variations,” and Francis Collins of the USA National Institutes of Health on “IHCC’s Critical Role in Global Crises such as COVID-19.” There were also six concurrent speed rounds covering topics such as how IHCC can work with the African Population Consortium, the Human Heredity and Health in Africa (H3Africa) Fellows, being an IHCC member, a deep dive into DAC, race and ethnicity in genomics, and obstacles to data sharing. These were followed by panel discussions on how IHCC cohorts pivoted to take on COVID-19 and how IHCC might be able to contribute to detecting emerging infections/pandemics in the future.

The meeting resulted in the following action items for IHCC leadership and members (owners of action items are noted in **bold**):

- The **Secretariat** will circulate information to cohort members on all IHCC projects presented during ICS4 (pilots, DAC, PRS) with investigator contact info. The **Secretariat** will also share project updates and investigator information on the IHCC website. **Cohorts** are encouraged to contact investigators if they would like to join the projects.
- The **Secretariat** will organize a WG leader meeting to ensure alignment on strategic objectives and action plans resulting from the breakout sessions. **WG leaders** will set up recurring WG meetings with support from the Secretariat. A new solicitation will be shared by the **Secretariat** inviting new members to the WGs, and existing membership/contact information confirmed by the **Secretariat**. **IHCC members** are encouraged to join/participate in any WG of interest by responding to the solicitation or contacting a WG leader.

- The **Secretariat** will follow up with cohorts participating in the European 1+ Million Genomes project for integration with IHCC if not already members.
- The **Executive and Scientific Steering Committees** will consider a survey of membership about how funding could best be utilized to build the community. They will implement the survey with support from the **Secretariat** and combine the request with other membership solicitations/surveys.
- The **Secretariat** will analyze feedback from speed-round moderators and support the resulting implementation plans.
- The **Scientific Steering Committee** will use the COVID-19 panel discussion to further consider what role the IHCC can plan to prepare cohorts such that they can provide ‘sentinel’ signals to public health officials and ensure data is made available to allow for robust response.
- The **Data Interoperability and Infrastructure WG** will:
 - Host a Data Atlas onboarding workshop with support from the **Secretariat**. The content will aim to streamline cohort mapping of data into the atlas registry and align with Common Infrastructure for National Cohorts in Europe, Canada, and Africa (CINECA), H3Africa Bionet training materials on Global Alliance for Genomics and Health (GA4GH) standards, cohort harmonization, and the Gene Expression: Computation and Knowledge Organization (GECKO) model. The **Secretariat** will record the workshop and make it available at the [IHCC Resource Center](#). Existing pages on the Cohort Data Atlas [overview](#) and [registry mapping instructions](#) will also be added to the [IHCC Resource Center](#) by the **Secretariat**.
 - Solicit feedback from membership and the research community about the utility of the Atlas and the data desired.
- The **Policy and Systems WG** will:
 - Contact membership to generate a prioritized list of specific obstacles encountered during sharing/collaboration, exploring issues beyond genomic data needs (e.g., consent standards for international data sharing).
 - Establish a reliable source for vetted resources as a “toolbox” based on needs and priorities identified by cohort members and funding to support this initiative as needed. Gaps in resources will generate needs for future IHCC policy development. This toolbox should be established quickly rather than waiting for a comprehensive list of resources.
 - Create a policy consult/helpdesk to capture needs and requests for assistance from cohort members as they navigate collaborative research in IHCC.
 - Develop relationships with regional and global cohort alliances in hopes to leverage similar/related policies in development by multiple groups.
- The **Scientific Strategy and Cohorts Enhancement WG** will:
 - Collect information from cohorts on research interests/priorities to enable matchmaking for future joint funding proposals.
 - Use this info to create a catalogue of cohort interests to share with funders. Create a similar catalog of industry/funder interests to share with cohorts. The WG may act as a matchmaker for cohorts \leftrightarrow funders/industry. Include local funders when possible.
 - Set up a platform (aside from mass membership emails) to solicit project/research ideas from any Investigator/cohort at any time (e.g., outside of a request for proposals). The platform may also enable sharing of unfunded proposals for feedback, soliciting additional collaborators, etc.
 - Work on a sustainable model to address lack of funding for large scale genotyping.
 - Emphasize environmental exposure data in project planning.
- The **Learning and Sharing WG** (newly named **Training, Sharing, Capacity Development WG**) will:

- Confirm the new WG leaders.
- Determine appropriate scope for this WG.
- Plan and propose funding for a series of workshops, seminars, symposia, training channel, etc.
- Plan cohort curriculum/IHCC “summer school/bootcamp” on high priority topics (e.g., data sharing, management and analysis, cohort design, biobanking). Consider virtual and live options with certificates of training.
- Highlight training/educational programs offered by cohort partners.
- Engage with the young investigator (YI) community to achieve a high level of participation in WG activities. With support from the **Secretariat**, establish a YI group/subcommittee with defined scope. Utilize YI input for educational and career opportunities of interest.
- Plan a future talk about the Tasso platform (contact: Michael Gaziano) for use in cohorts without resources for phlebotomy.
- Plan a talk on best practices for collaboration with industry (perhaps one on industry perspective and another on cohort perspective).
- Regarding cohorts in LRS:
 - The **Scientific Steering Committee** will consider creation of a LRS/cohort liaison to support collaboration of LRS cohorts on IHCC projects. The role can provide temporary assistance to help the cohort navigate what is needed to participate and how to implement collaborative agreements.
 - The **Learning and Sharing/Training, Sharing, Capacity Development WG** will prioritize training programs related to LRS challenges: Biobanking protocols, data sharing, management, and analysis.
 - The **Policy and Systems WG** will consider the IHCC role in outreach to policy makers specifically in LRS where research infrastructure is more limited and advocate for benefits of cohorts (especially when applying for funding).
 - The **Scientific Strategy and Cohorts Enhancements WG** will plan and propose funding for a large-scale collaborative project(s) with high-tech element(s) to improve capacity in LRS cohorts (e.g., Nightingale project, genotyping). In relation to this future project or IHCC at large, the WG will establish processes to assemble cohorts and negotiate with vendors for bulk rates. They will survey membership for who has samples that need to be converted to genotype data to support this negotiation.
 - The **Secretariat** and **Executive Committee** will create/continue to support a framework conducive for funding with cohorts (LRS and others). Experience during the cross-cohort pilot projects has demonstrated advantages for contracting with the consortium rather than individual cohorts. The **Secretariat** (and/or external source) may support negotiations and contracting with industry and universities, international funders, etc.
 - The **Executive Committee**, along with the **Scientific Strategy and Cohorts Enhancement WG** will establish a pre-competitive environment for venture capital and industry funders to have limited, time-stamped, or non-exclusive access to cohorts (modeled after the UK Biobank Proteomic Pharma Project).

Videos of all presentations given during this meeting can be found on the IHCC website [here](#).

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