



International 100K Cohort Consortium

VIRTUAL WORKING GROUP MEETING AND WORKSHOP SUMMARY

Virtual Meeting
Zoom

November 9th and 11th, 2020

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

Vision for success:

TO CREATE A GLOBAL NETWORK FOR TRANSLATIONAL RESEARCH THAT UTILIZES
LARGE COHORTS TO ENHANCE THE UNDERSTANDING OF THE BIOLOGICAL AND GENETIC
BASIS OF DISEASE AND IMPROVE CLINICAL CARE AND POPULATION HEALTH

IHCC Virtual Working Group Meeting and Workshop 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. A Third International Cohorts Summit (ICS3) took place virtually in 2020 due to the COVID-19 pandemic. A virtual Working Group and Workshop was scheduled ~six months after this event to continue the momentum of the IHCC and update membership on consortium activities.

The virtual meeting objectives included:

- To revisit the objectives and key actions resulting from the May 2020 ICS3 and update the IHCC membership on progress to date.
- To engage the entirety of the IHCC membership in developing the key topics to establish a cohesive strategic plan that addresses the vision, scientific direction, and unique challenges of global cohort collaboration.

Session 1 followed up on Objective 1 (to galvanize the IHCC around a visionary charter and path forward) and 2 (to examine how IHCC can rapidly mobilize worldwide cohorts to address the COVID-19 pandemic) from ICS3. Members were updated on progress on the Membership Agreement (MA) and Implementation, IHCC Policy documents, and funded cross-cohort COVID-19 research projects. Session 3 followed up on Objective 3 (to introduce the IHCC to a cohort's atlas that can be used to stimulate/enable collaborations among cohorts) and 4 (to engage the entirety of the IHCC membership in developing the key topics to chart a scientific agenda that can only be achieved by assembling cohorts and their data) from ICS3. Members were updated on the Global Cohorts Data Atlas development and initiatives of the Scientific Strategy and Cohorts Enhancements Working Group projects as well as several additional funded cross-cohort research projects. Sessions 2 and 4 featured interactive workshops to support the IHCC Strategic Planning process. The results of these sessions will be incorporated into the IHCC Five-year Strategic Plan. The final report summarizing the strategic plan will be available to members and public in 2021.

The meeting resulted in the following action items for IHCC leadership and members:

- The revised MA will be distributed by the Secretariat to cohorts for review as needed. This distribution will include language summarizing changes for those cohorts who have already ratified the MA and emphasize that this is not a legal document but rather an academic agreement to be signed by an investigator rather than an institutional official. The communication will also include language about what a cohort may gain vs. risk when they sign the MA and reiterate that data sharing is agreed to with each collaboration proposal. The remaining cohorts are encouraged to sign/return by December of 2020 or share their concerns. The MA implementation steps have started and will aim to be finalized by ICS4.
- Cohorts are encouraged to visit the Global Cohorts Data Atlas [browser](#) and provide feedback to the Atlas team for further development (ihcc-browser@googlegroups.com). Cohorts are also encouraged to submit their data to the Atlas Registry and share their use-cases for Atlas queries to support further development of the harmonization methods and browser interface.

- The policy and data sharing document updates were presented and will be shared with the Steering Committee at an upcoming meeting for provisional approval; a formal approval process will take place once the new Scientific Steering Committee has been formed.
- Cohorts are encouraged to share fundamental issues that the Policy and Biodata Sharing Working Group should prioritize and share policy/data-sharing resources that might be helpful for other IHCC members.
- Cohorts are encouraged to respond to the data sharing [survey](#) by December 11, 2020.
- Cohorts with relevant data or interest in joining any of the ongoing cross-cohort projects should contact the investigators that presented at the workshop. If contact information is needed, contact the IHCC Secretariat.
- Members are encouraged to join any of the IHCC Working Groups by contacting the Working Group leaders.

Videos of the presentations given during this meeting are [here](#) (Day 1) and [here](#) (Day 2).

Abbreviations

AD	Alzheimer's Disease
BMI	Body mass index
CEOi	Global CEO Initiative on Alzheimer's Disease
CZI	Chan Zuckerberg Initiative
CRC	Colorectal Cancer
COVID-19	Coronavirus Disease
DAC	Davos Alzheimer's Collaborative
EC	Executive Committee
EMBL-EBI	European Molecular Biology Laboratory - European Bioinformatics Institute
GRS	Genetic Risk Score
G2MC	Global Genomic Medicine Collaborative
GA4GH	Global Alliance for Genomics and Health
GWAS	Genome-Wide Association Study
HIRO	Heads of International Research Organizations
ICDA	International Common Disease Alliance
ICS3	Third International Cohorts Summit
ICS4	Fourth International Cohorts Summit
IHCC	International HundredK+ Cohorts Consortium
LD	Linkage Disequilibrium
LMIC	Low- and/or Middle-Income Country
MA	Membership Agreement
NIH	National Institutes of Health (USA)
OPICO	Opioid Cohort Consortium
OWL	Ontology Web Language
PRS	Polygenic Risk Score
SPSC	Scientific Projects Sub-Committee
SSC	Scientific Steering Committee
SNP	Single Nucleotide Polymorphism
SOP	Standard Operating Procedure
SWG	Scientific Working Group
TIN	Target Identification Network
UN	United Nations
WEF	World Economic Forum
WHO	World Health Organization
WT	Wellcome Trust

Note: Cohort abbreviations can be found in the list of participating IHCC Member Cohorts at the end of this document.

VIRTUAL WORKING GROUP MEETING AND WORKSHOP

Hosted by the Global Genomic Medicine Collaborative (G2MC)

Meeting Summary

Day 1: November 9, 2020, 12:00 – 16:30 UTC

MEETING INTRODUCTION AND BACKGROUND

CHAIR: TERI MANOLIO, MD, PHD

12:00-12:10 UTC

Welcome and Introductions – Geoffrey Ginsburg, MD, PhD (*Duke University, USA*)

IHCC welcomes several new cohorts: Generation Victoria (Australia), Kathmandu Cohort (Nepal), and Makerere University Population Cohort (Uganda), bringing IHCC's total membership to 110 cohorts.

The IHCC vision was formulated in 2018: *to create a global network of large cohorts (with multi-dimensional data from diverse populations) for translational research that will be maximally utilized to enhance scientific understanding of the biological, environmental and genetic basis of disease and to improve population health.* This vision will be considered during the strategic planning sessions in this workshop.

This meeting takes place six months after the Third International Cohorts Summit (ICS3), held virtually in May of 2020. During this gathering, IHCC aimed: to galvanize around a visionary charter and create a path forward, to examine how IHCC could rapidly mobilize worldwide cohorts to address the COVID-19 pandemic, to demonstrate the Global Cohorts Data Atlas to stimulate discovery and collaboration between cohorts, and to engage the entirety of membership in developing the IHCC scientific agenda. Building upon the momentum at ICS3, the meeting objectives for this gathering included:

- To revisit the objectives and key actions resulting from the May 2020 ICS3 and update the IHCC membership on progress to date.
- To engage the entirety of the IHCC membership in developing the key topics to establish a cohesive strategic plan that addresses the vision, scientific direction, and unique challenges of global cohort collaboration.

SESSION 1 – IHCC POST-SUMMIT PROGRESS

CHAIR: TERI MANOLIO, MD, PHD

12:10-14:00 UTC

Introduction and Review of ICS3 Objective #1 and Key Actions – Teri Manolio, MD, PhD (*National Human Genome Research Institute, NIH, USA*)

Objective #1 from ICS3 was to galvanize the IHCC around a visionary charter and path forward (defining the IHCC organization, mission, membership, partnership opportunities, and industry engagement). During ICS3, several key actions were identified with regard to this objective. Their current status is noted below:

Key Action	Status
Provide feedback on IHCC Charter as needed. A formal ratification process will follow in June 2020.	Complete: ratification survey circulated and tallied
Provide responses to the data sharing survey by June 5, 2020 to inform the IHCC Core Data Sharing Principles.	Complete: request circulated and responses adopted
Provide additional comments on policy documents as needed by May 22, 2020 to Laura Lyman Rodriguez. Final versions will be approved by the SSC and distributed to membership.	In Progress: policies under review for ratification by standing Steering Committee
IHCC members interested in joining the working groups (Policy and Biodata sharing, Data and Infrastructure, or Scientific Strategy) are encouraged to contact the team leads or IHCC Secretariat.	Ongoing

Membership Agreement Update - John Connolly, PhD (*Center for Applied Genomics, Children's Hospital of Philadelphia, USA*)

The Membership Agreement (MA), previously referred to as the Membership Charter, was the product of a working group led by Mary De Silva and John Connolly, with support from several IHCC members across diverse geographies, research backgrounds, and demographics. After the MA was presented at ICS3, the MA working group collected feedback from cohort members and several cohorts have ratified the MA. They have created a provisional second draft with minor clarifying edits.

The main guiding principles for the MA are below:

- Transparency in process, practice, and outcomes in all projects and policies through democratic decision making, and open and timely access to research outputs generated through any IHCC activities.
- Fairness, inclusivity, and equity for all members across geographies, datatypes (including non-genomics data), age-span of cohort, and type of science (e.g., social science, biomedicine, epidemiology).

The MA is not a legal document but rather aims to outline the requirements and expectations by which members of IHCC agree to collaborate. The MA proposed a governance structure under the leadership of the Executive Committee (EC), and Scientific Steering Committee (SSC) with support from a Scientific Projects Sub-Committee (SPSC) and three current Working Groups: Data Standards and Interoperability, Scientific Strategy and Cohorts Enhancements, and Policy and Bio-data Sharing.

The EC, comprised of a chair, two co-chairs, and four additional members selected by the SSC, is responsible for the strategic direction of IHCC. They may strategize funding and perform the financial administration of the organization. They will direct administrative activities and resolve any disputes. The SSC, comprised of nominees voted upon by IHCC members, is responsible for the scientific direction of IHCC. They will approve new cohort members, approve goals set out by the EC, commission and approve publications, and approve IHCC policies. In line with the goals of IHCC to foster collaboration between academia and industry, the MA was updated since May to add an industry representative to the SSC. The SPSC is responsible for reviewing/approving proposed IHCC projects and approves access to IHCC managed data. This committee was convened during the COVID-19 proposal review process in September - October and has established some working policies. The existing Working Groups have representatives on the SSC. Additional Working Groups may be added and/or removed in the future.

The MA lists criteria to be an IHCC member: 100,000+ participants enrolled (unless from disadvantaged population), longitudinal follow up for health outcomes, not selected for specific disease, access to

biological samples, and willingness to share data or metadata with IHCC members. Each cohort member has one vote in IHCC decisions. Affiliate members and industry members may not meet cohort criteria but have valuable expertise and are welcome to participate in IHCC activities, but do not vote in IHCC decisions.

To date the MA has been ratified by 31 sites with another two pending institutional review. One cohort had concerns about intellectual property language, which was addressed by clarifying wording as IHCC does not intend to limit any cohort's intellectual property. The MA has been reviewed by IHCC legal counsel and some additional minor revisions were made. IHCC will soon share the updated MA with members and the SSC will have the opportunity to approve or reject it.

While members may continue to engage with IHCC without ratifying the MA, it will impact access to IHCC resources (e.g., IHCC data, project funding). The MA was distributed to sites in a draft form, which may have limited certain institutions from reviewing it. IHCC will distribute the revised MA (with a version control date) to the cohorts in the coming months. The "ask" to cohorts will clarify the benefits of the agreement and lack of negative implications in agreeing to a non-legal document.

Roadmap to Implementation and Next Steps – Brittany Zick, MSc (IHCC Secretariat, USA)

While the ratification process is ongoing for the MA, the Secretariat has been considering how to implement the requirements outlined in this document. While the MA outlines *what* the IHCC aims to do as an organization, additional information is needed on *how* the IHCC will accomplish these aims. In an effort to ensure transparency, accountability, and traceability, IHCC will create numerous version controlled standard operating procedures (SOPs). These would become available to members on the [IHCC Resource Center](#) and made available to funders upon request.

To launch this process, the Secretariat has prioritized certain domains of the MA for immediate implementation, with the goal of implementing all domains by the Fourth International Cohorts Summit (ICS4) in 2021. The Vision domain of the MA is being operationalized through the strategic planning process. In addition, the Secretariat is currently focused on implementing the Governance, Membership, Data Management, Data Sharing/Access, and Amendments (for version control) domains. Implementing each of these domains will require one or multiple SOPs; an initial list has been identified but is not exhaustive. Each SOP has been assigned a content owner who will draft and revise the SOP (e.g., Secretariat, Workgroup leaders, etc.). For each domain and relevant SOP, the assigned content owner will examine the MA and any supporting documents/previous non-formalized procedures used by IHCC. They will gather additional data from relevant stakeholders (e.g., SSC, members) and propose implementation actions to include immediate next steps and adoption of an SOP. All SOPs will be reviewed and approved by the SSC to ensure that IHCC members have input on how the IHCC operates. As an example, one of the immediate priorities for MA implementation is the formation of the SSC. This committee should have 15 voting members including the workgroup leaders as well as various elected cohort members with three-year terms. Several details were discussed with the current SC to gather input (e.g., how many subsequent terms can an elected member hold on the SSC? Are there eligibility requirements?). Using this information, the content owner drafts SOPs and other supporting documents needed to operationalize this element of the MA (e.g., SOP for SSC elections, expectations of SSC members). The content owner may also propose immediate next steps leading to implementation (e.g., current SC acts as SSC until new members are elected, host election of new members prior to ICS4).

Implementation of the MA will happen in stages, but eventually will document and standardize processes that members have only agreed to theoretically. This will increase transparency for members

and funders and ensure that all stakeholders understand expectations for interactions with IHCC and its membership. Documenting these procedures will enable IHCC to adapt and iterate policies and procedures as the needs of the organization and membership evolve.

IHCC Policy Update – Laura Lyman Rodriguez, PhD (*Patient-Centered Outcomes Research Institute, USA*)

Three policies were presented at ICS3 for initial feedback. After this meeting, several cohorts submitted written input for these draft documents and several changes were made. Each policy/guidance document was created in alignment with IHCC values including: open and timely dissemination of research findings, transparency within IHCC activities, and promotion of inclusivity of cohorts within IHCC activities.

Publication Policy: This document supports the timely and open dissemination of IHCC research and findings as well as fair and equitable opportunity for IHCC Members to participate in authoring IHCC publications. The policy defines the types of publications that will need to follow the policy (e.g., IHCC Consortium paper vs. Project paper vs. non-Consortium paper). It also outlines concepts of timeliness, authorship contributions, open access requirements, and the need for a Publication and Authorship Plan at the time of project proposal. The Policy includes a sample cohort acknowledgment statement and template Publication and Authorship Plan. Based on member feedback since ICS3, the Policy team clarified language for what is a Consortium vs. non-Consortium paper and thus would not need to follow this policy. In addition, language was added to encourage inclusion of and authorship recognition for junior investigators, acknowledgement of research participants in cohort citation statements, and explicit allowance for organizational review of publications before submission.

Guidance for Collaboration with Industry: this document supports the establishment of IHCC collaborations with industry partners through agreements that promote the IHCC vision and values. This document is written as a guidance resource for cohorts when establishing partnerships with industry rather than a binding policy. The guidance outlines various types of collaborations possible for IHCC cohorts and defines the principles upon which partnerships should be built. These points should be considered up front when drafting collaboration agreements to ensure transparent and equitable partnerships. The guidance includes a checklist for cohorts as a resource rather than a template. Cohort feedback since ICS3 led to the incorporation of more explicit language about defining the reciprocal interests of forming partnerships, expanded the examples of stakeholders that may be involved to realize value for partners or study stakeholders, clarified that guidance applies only to IHCC approved projects involving industry partners, and clarified that public posting of collaboration agreements would only be necessary at a high level (summary rather than all details).

Core Data Sharing Principles: establishes fundamental data sharing expectations and provide a foundation for future development of data sharing policies for IHCC activities. The principles leverage the Framework for Ethical Foundation from Global Alliance for Genomics and Health (GA4GH). The principles assume locally appropriate research consent and legal oversights are in place. The listed foundational principles are assumed to be followed; these are basic expectations to promote IHCC strategic goals and values while respecting cohort policies. Aspirational principles, which build upon the foundational principles, are also listed. They serve to advance IHCC and cohorts forward on long-term data sharing goals (e.g., streamlined data access). Since ICS3, the use of these principles was further clarified to be used alongside cohort-specific capacities/policies in developing IHCC project data sharing plans. These principles represent a living document that will be updated with IHCC project experience.

Each of these policies will be provisionally reviewed and approved by the current SC and formally approved by the SSC once it is formed. The formal approval of the IHCC policies will support approvals of the MA by additional cohorts, as the MA makes reference to these documents. Current versions of the policies may be found on the [IHCC Resource Center](#). IHCC members from around the world are encouraged to join the Policy and Biodata Sharing Working Group by contacting Laura Lyman Rodriguez.

IHCC project teams are encouraged to contact the Policy and Biodata Sharing Working Group with data sharing issues as they arise. The group may be able to act in a supportive consulting role but also add these issues to the priority list of IHCC needs. The Policy and Biodata Sharing Working Group circulated a survey to cohort members about their needs to help identify some of these priorities in advance of large multi-cohort projects. There are eight questions with both pre-populated and open-text field responses. The data sharing [survey](#) collects information on data types, restrictions of data storage and analysis, limitations from informed consent documents, legal and cost considerations, etc. Twenty-seven cohorts have responded with a solid list of needs to prioritize, but new and existing cohorts are encouraged to fill out the survey as well.

Introduction and Review of ICS3 Objective #2 and Key Actions – Teri Manolio, MD, PhD (*National Human Genome Research Institute, NIH, USA*)

Objective #2 from ICS3 was to examine how IHCC can rapidly mobilize worldwide cohorts to address the COVID-19 pandemic. During ICS3, several key actions were identified with regard to this objective. Their current status is noted below:

Key Action	Status
Provide responses to the IHCC COVID-19 cohort survey if not already complete (will be recirculated via email to cohorts)	Complete: June 2020
Indicate interest in joining any of the COVID-19 SWGs by May 12, 2020. Contact Eric Plummer to join.	Complete: 3 SWGs formed (Epidemiology, Mental Health, Biospecimen)
Cohorts measuring the impact of protective mental health interventions for COVID-19 are encouraged to contact Wellcome Trust (Jordan Smoller, Andre Brunoni, Sarah Bauermeister)	Complete: 16 cohorts / 10 countries
For COVID-19 research studies, register on the ICDA COVID-19 Host Genomics Initiative	Status: Complete and ongoing

IHCC 2020 COVID-19 Mobilization – 2020 Funded Projects

Global mental Health Impact of the COVID-19 Pandemic – Sarah Bauermeister, PhD (University of Oxford, UK)

This project will be co-led by Sarah Bauermeister (UK), Andre Brunoni (Brazil), and Jordan Smoller (USA). The COVID-19 pandemic has presented unprecedented challenges to global mental health, particularly among first responders, healthcare workers, and those with pre-existing mental health conditions. The pandemic has disrupted communities and social connections (e.g., families, work, schooling), and impacted emotional development across the lifespan. Unemployment, economic insecurity, and disruption to care systems for mental health conditions has led to further distress.

In response to this global crisis, this study aims to first categorize the availability of IHCC and Dementias Platform United Kingdom (DPUK) cohorts that have mental health assessment data during and/or after the pandemic. The project will create a harmonized set of domains/variables to build an international, cooperative platform and enable cross-cohort analysis in conjunction with the IHCC Data Standards and

Interoperability Working Group using a common data model (DPUK C-Surv) to bring these data sets together.

The second aim will conduct cross cohort analysis to address key questions such as:

- How is the pandemic affecting rates of mental health symptoms and disorders over time?
- Which individual level factors predict risk and resilience?
- How will these changes differ by demographic factors such as age, sex, race, ethnicity, geography and at-risk groups (e.g., pre-existing mental health disorders)?
- How do social determinants of health (e.g., socioeconomic status, education, occupation, discrimination, access to healthcare/insurance, density of congregate or multigenerational housing) modify the impact of COVID-19 on mental health outcomes?

The project team will define quantitative and categorical mental health outcomes, use longitudinal analytical methods, and combine results using meta-analysis. They will conduct focused analysis on social determinants of health using univariate, interaction and mediation analysis.

The third aim will characterize the neuropsychological and cognitive manifestations or complications of COVID-19 infection using some of the at-risk groups identified in the second aim. The project will examine changes in neuropsychological and cognitive functioning during the pandemic period compared to defined reference periods prior to the pandemic and compare individuals who have been infected to those who have not.

Exposures to be evaluated include some COVID-19 related (e.g. infection status, symptoms, severity, etc.), medical comorbidities (e.g. obesity, diabetes, etc.), psychosocial stressors (e.g. duration of lockdown, housing density, occupational exposures to COVID-19, etc.), economic vulnerability (e.g. healthcare access, insurance, food/housing insecurity, etc.), resilience factors (e.g. social connection supports, physical activity, dietary factors, education, etc.), and genetics (if available). Covariates such as demographics, social determinants of health, high-risk occupations, psychiatric history, substance use, genetics, etc. will also be considered in addition to outcome data when available (e.g., mental health symptoms, suicidality and self-harm, psychiatric disorders, mental health treatment, cognitive function, etc.). This project should take place over approximately a one-year period, with initial manuscript submission targeted for late 2021. Several cohorts have already expressed interest in participating and additional interested cohorts are encouraged to contact Sarah Bauermeister.

Strengthening biospecimen collection for Global Longitudinal Population Studies in the COVID-19 era – John Chambers, MD, PhD (*Lee Kong Chian School of Medicine, Singapore*)

This project will be co-led by John Chambers (UK, Singapore), Laura Lyman Rodriguez (USA), Catterina Ferreccio (Chile), Anu Kasturiratne (Sri Lanka), Khadija Khawaja (Pakistan). There are current knowledge gaps around best practices for biospecimen collection in longitudinal population studies and optimal strategies in low- and middle-income countries (LMICs). This project aims to strengthen biospecimen collection methods, promote sample documentation, and facilitate sample sharing amongst cohorts aligned to IHCC, with an emphasis on cohorts from underrepresented populations. One project theme will generate knowledge/resources on best practices for biospecimens, regulatory and ethical frameworks, and current biospecimen collections. This resource will be community driven, with participating cohorts sharing their knowledge and insight based on experience and challenges. The second theme will focus on a demonstration project with biospecimen collection in one or more underserved settings. This will strengthen the approach to biospecimen collection, act as a springboard for future larger efforts, and target overlapping goals with the Chan Zuckerberg Initiative (CZI) Human Cell Atlas. Current collaborators cover six of the World Health Organization (WHO) / United Nations (UN)

global regions including Europe, North America, South America, Middle East and North Africa, South Asia, and South East Asia. Project work will take place over 12 months with goals to secure additional external funding after the first year.

Novel corona virus host susceptibility study in South Africa (COVIGen-SA) – Michele Ramsay, PhD (University of Witwatersrand/H3Africa, South Africa)

This project is co-led by June Fabian, Kobus Herbst, Emily Wong, Stephen Tollman, Kathy Kahn, Scott Hazelhurst, Ananyo Choudhury, and Andrew May. There appears to be lower prevalence of COVID-19 in Africa but the reasons for this are not well understood. Hypotheses include incomplete data or a lack of testing, increased immune protection from other vaccines or viruses, population demographics, and differences in co-morbidities. However, there may also be a genetic component. This study aims to understand the host genetics of SARS-CoV-2 infection and disease progression in South African populations to generate knowledge to inform a precision medicine approach to the COVID-19 pandemic. Participants will be included from the South African Population Research Infrastructure Network (SAPRIN) cohort (IHCC member) as well as several other non-IHCC South African cohorts to achieve adequate sample size of severe COVID-19 cases (Baragwanath Hospital-based Studies, Vukuzazi, Agincourt, Ezintsha, AWI-Gen). The project will explore host genomic contributions to COVID-19 outcomes in black South African patients, leverage partnerships to identify clinical and demographic features that contribute to vulnerabilities in COVID-19 outcomes (e.g., age, sex, HIV, TB, cardiovascular diseases, diabetes) and gene-environment interactions, and enhance the study and increase power and continental reach by partnering with other studies in Africa. The short-term study goals will be to pilot genotyping with 576 Black South African subjects with COVID-19 and ~5000 controls from the AWI-Gen H3Africa cohort and perform genetic association analysis and validation studies. Long term, the study will increase sample size and include subjects from other African cohorts.

Session 1 – Summary and Next Steps – Teri Manolio, MD, PhD (National Human Genome Research Institute, NIH, USA)

The revised MA will be distributed by Eric Plummer to cohorts for review as needed. This distribution will include language summarizing the change for those cohorts who have already ratified the MA and emphasize that this is not a legal document but rather an academic agreement to be signed by an investigator rather than an institutional official. The communication will also include language about what a cohort may gain vs. risk when they sign the MA and reiterate that data sharing is agreed to with each collaboration (project) proposal. The remaining cohorts are encouraged to sign/return by December of 2020 or share their concerns. The MA implementation steps have started and will aim to be finalized by ICS4.

The policy and data sharing document updates were presented and will be shared with the SC at an upcoming meeting for provisional approval; a formal approval process will take place once the new SSC has been formed. Cohorts are encouraged to share fundamental issues that the Policy and Biodata Sharing Working Group should prioritize, share policy/data-sharing resources that might be helpful for other members, and respond to the data sharing [survey](#) by December 11, 2020.

SESSION 2 – IHCC STRATEGIC PLANNING WORKSHOP

CHAIR: GEOFFREY GINSBURG, MD, PHD

14:30-16:30 UTC

Strategic Planning Background and Introductions – Geoffrey Ginsburg, MD, PhD (Duke University, USA)

IHCC was founded with the understanding that many large cohorts had been established worldwide but each of them was constrained by size, ancestral origins, and geographic boundaries. Combining data from these cohorts would enable addressing pressing global health questions that none can answer alone, enhancing the value of each and leveraging their investments. The NIH began compiling data on these large cohort programs in 2015 and in 2017, the Heads of International Research Organizations (HIROs) agreed the cohorts should be brought together to encourage these data sharing opportunities to maximize investments. With support from the HIROs, WT, and NIH, the First International Summit was organized at Duke University (USA) in 2018. There were 100 attendees from 24 countries from IHCC's 60 cohorts amassing 30 million participants. After a Second Summit in Iceland in 2019, the Third Summit was held virtually in 2020 due to the COVID-19 pandemic. Membership now stands at 110 cohorts across more than 40 countries including more than 50 million participants.

As IHCC has grown and secured funding for cross-cohort initiatives, unique challenges have been identified such as the complexity of data, lack of standardization and harmonization of questionnaires, inability to move data/samples due to regulatory restrictions and national laws, lack of standards for phenotyping and health outcomes, and cross-cultural differences in risk tolerance and privacy. IHCC has aimed to answer scientific questions that could only be accomplished at this scale, such as examining risks associated with rare exposures and outcomes, generalizability of risk factors and associations, ancestry-specific determinants of health, social and cultural determinants of health, country and cohort specific risk predictions, and human knock-out identification and phenotyping. IHCC developed working groups to develop information technology to promote discoverability of the cohorts and sharing of data, develop a robust scientific plan that leverages cross cohort collaboration and maximizes input from the global scientific community, and develop the policy agenda to advance data sharing and engagement with industry.

IHCC will continue to develop ways to leverage the cohorts through expansion of the Global Cohorts Data Atlas, multi-cohort demonstration projects, engagement of LMIC and special population cohorts, dissemination of findings and publications, cohort enhancements (e.g., sequencing, multi-omics capabilities, etc.). Many of these points will be more richly detailed through development of the five-year strategic plan.

Strategic Planning Process and Objectives – Laura Runnels, MPH (LAR Consulting, USA)

The strategic planning process was initiated in September of 2020 with small group meetings and establishment of the strategic planning group. This process should answer the following question for IHCC:

- What is the context in which we are planning?
- What is IHCC's purpose given its unique position?
- What might accelerate or hinder IHCC's efforts?
- What do we want to accomplish and how will we know we are achieving it?
- How can we best organize and operate to get things done and hold ourselves accountable?

Thus far in the process, the leadership team has been convened and the strategic planning group has reviewed the historical context of the organization and finalized the timeline. Desk research was conducted and data collection tools (e.g., surveys) were designed for use among membership. In the coming months, there will be a series of planning workshops, discussions, and interviews with members and stakeholders. Membership will be kept informed of progress, and the plan will be finalized in February of 2021.

During the first strategic planning workshop, attendees were moved into breakout rooms to consider the major barriers and facilitators for the IHCC mission. Details on outcomes of this workshop will be documented in the Strategic Planning Report, to be made available in early 2021.

Day 1 Closing Remarks – Geoffrey Ginsburg, MD, PhD (Duke University, USA)

Day 2: November 11, 2020, 12:00 – 16:30 UTC

Welcome and Introductions – Peter Goodhand (Global Alliance for Genomics & Health, Canada)

SESSION 3 – IHCC POST-SUMMIT PROGRESS

CHAIR: PETER GOODHAND

12:05-14:00 UTC

Introduction and Review of ICS3 Objective #3 and Key Actions – Peter Goodhand (Global Alliance for Genomics & Health, Canada)

Objective #3 from ICS3 was to introduce the IHCC to a cohort’s atlas that can be used to stimulate/enable collaborations among cohorts. During ICS3, several key actions were identified with regard to this objective. Their current status is noted below:

Key Action	Status
Cohorts may continue to provide data dictionaries for the IHCC Global Cohorts Data Atlas development to ihcc-browser@googlegroups.com . IHCC cohort data will be further populated in the atlas. Members are encouraged to provide feedback to Data and Infrastructure Team on use cases for atlas queries. This team will establish a compelling set of research and clinical showcase applications. COVID-19 phenotyping will be added to the atlas. Cohorts are interested in cross-cohort COVID-19 research may also consider providing data dictionaries for harmonization and cohort discovery.	In Progress and ongoing
An IHCC Resource Center with relevant data tools and other cohort resources will be created and shared on the IHCC website.	Complete and active (http://ihccglobal.org/resource-center/)

Global Cohorts Data Atlas Team Update – Philip Awadalla, PhD (Ontario Institute for Cancer Research, Canada), Thomas Keane, PhD (European Bioinformatics Institute and Global Alliance for Genomics & Health, UK)

The IHCC Data Standards and Interoperability Working Group has been creating an interoperable platform that captures various levels of data from the IHCC cohorts. To establish feasibility, initial efforts have been focused on metadata. The Global Cohorts Data Atlas browser, initially demonstrated during ICS3, has been further developed since the meeting concurrent with data harmonization efforts. These activities feed into a larger global development strategy for the atlas to serve both IHCC and general research community needs.

Status of the Global Cohorts Data Atlas – Christina Yung, PhD (*Ontario Institute for Cancer Research, Canada*)

After ICS3, the atlas team incorporated feedback to develop the atlas browser into a production quality product with automated cloud hosting. Five cohorts (Africa Health Research Institute, Genomics England, Golestan Cohort Study, Korean Genome and Epidemiology Study, South African Population Research Infrastructure Network) submitted data dictionaries which were harmonized and uploaded into the atlas browser to replace the previously populated mock data used for demonstration. The current atlas is live and publicly available at <https://atlas.ihccglobal.org/> where users can search for cohorts that meet their query criteria.

The left panel of the browser shows selectable search criteria including socio/demographic information, healthcare information, physiological elements, non-pharmacological intervention, medications, diseases, lifestyle and behaviors, Principal Investigator(s), methodology, enrollment (cohort size), sample data types, cohort attributes (administrative information), phenotypic clinical data availability, genomic data availability, environmental data availability, biospecimen data availability, countries, and cohort names. When one or more criteria is selected, the queried cohorts along with their details are displayed in the main panel of the browser. The search panel on the left is currently quite lengthy; the atlas team anticipates that this design will be updated for easier use in the future. Cohorts are encouraged to visit the [browser](#) and provide feedback to the atlas team for further development (ihcc-browser@googlegroups.com).

Lessons learned from the Atlas Pilot – Melanie Courtot, PhD (*European Bioinformatics Institute, EMBL-EBI, UK*)

Since the demonstration at ICS3, the project team has harmonized heterogeneous metadata from five cohorts to create one integrated dataset for the atlas browser. Cohorts collect data attributes that are not indexed/labeled uniformly, which creates a challenge for an automated query like those in the atlas browser. The team has tried to address this challenge in part by requesting data in a standard format (CSV) and establishing text-mining methods for data mapping.

A cohort [registry](#) was developed using ontology web language (OWL) to load the data dictionaries in the browser and provide interoperability of mapping tools. There is a submission pipeline to enable cohorts to submit data directly by uploading their data to the cohort registry in the standard CSV format. The registry uses an admin console with file versioning under GitHub. The pipeline then uses text-mining to suggest mapping to be reviewed and updated by the cohort owners; these are currently utilizing several tools in the EMBL-EBI semantic suite for ontology annotation, cross referencing, and search. Mapping is currently functional for English data dictionaries based on the underlying mapping tools. Once data mapping is approved, the files are automatically converted and loaded into the registry and pushed up to the browser. As more data is uploaded, the text-mining will become more accurate for mapping. The atlas is currently cross referenced to the Maelstrom high-level categories and there is an ongoing effort with the Maelstrom team to enable import/export of cohorts in both platforms. The team will continue design with incorporation of Maelstrom and other cohort query portals to the extent possible for functionality across these platforms.

The atlas team plans to expand the content of the atlas and invite additional cohorts to submit their data to the registry and step through the mapping process. Cohorts and researchers are also encouraged to share their use-cases for atlas queries to support further development of the harmonization methods and browser interface. The IHCC cross-cohort scientific projects recently awarded may serve as use-cases for the atlas.

Global Cohort Data Atlas Expansion, Opportunities, and next steps - Philip Awadalla, PhD (Ontario Institute for Cancer Research, Canada), Thomas Keane, PhD (European Bioinformatics Institute and Global Alliance for Genomics & Health, UK)

The Global Cohorts Data Atlas is a first step in the discovery process; the Data Standards and Interoperability Working Group is also planning for the future of scalable cross-cohort analysis. This development roadmap will involve consideration of jurisdictional restrictions, federated vs. centralized vs. hybrid data models, new technologies for cross-cohort integration, interoperability standards, etc. The atlas is leveraging existing cross-cohort initiatives to help solve some of the challenges for an interoperable data platform (e.g., Common Infrastructure for National Cohorts in Europe Canada and Africa - CINECA). Use cases will be valuable in shaping the next steps of this platform; cohorts are encouraged to share their needs with the atlas team.

Discussion among meeting attendees revealed several ideas for next steps of the data platform. In the future, there may be some level of in-platform analysis without downloading data; cohort owners may be able to support analysis of their data without giving access to it. This will require buy-in from cohorts of what type of queries are allowable. There may be options for levels of data access depending on institutional affiliation or cohort permissions. It is unlikely that one data approach will fit all cohort needs; some may be able to store data in a centralized place for analysis while others may not.

Introduction and Review of ICS3 Objective #4 and Key Actions – Adam Butterworth (University of Cambridge, UK)

Objective #4 from ICS3 was to engage the entirety of the IHCC membership in developing the key topics to chart a scientific agenda that can only be achieved by assembling cohorts and their data. During ICS3, several key actions were identified with regard to this objective. Their current status is noted below:

Key Action	Status
IHCC will collectively develop a five-year roadmap.	In Progress
To join the Davos Alzheimer’s Collaborative, contact Drew Holzapfel and/or attend the scheduled calls on May 19/20, 2020.	Complete and ongoing (~30 cohorts engaged)
Scientific Strategies team will launch three to five scientific initiatives with a 12–18-month timeframe using a federated approach with an emphasis on global diversity more than -omics.	Complete (6 programs approved for funding)
Collaborate on the COVID-19 specific activities (see Objective Two)	Complete
Continue to develop a shared scientific agenda through implementation of the Charter (membership agreement) with new governance structure (elected members of the Steering Committee, etc.) and virtual working group meeting in ~six months	In Progress (virtual working meeting ongoing)

Progression of the IHCC Shared Scientific Agenda

2020 Pilot Project Selection – Process and Results – Eric Plummer, PMP (IHCC Secretariat, USA)

Six months after ICS3, there are now six funded cross-cohort projects. This process began with a proposal solicitation issued to all cohorts and facilitated by the Scientific Strategy and Cohorts Enhancements Working Group in June of 2020. Frequently-asked-questions and additional budget guidance were issued in July to support proposal submissions. IHCC members were also requested to join the Scientific Projects Sub-Committee (SPSC) to participate in evaluation of the proposals. With numerous volunteers, the SPSC included cohort members, industry representatives, and funders. This group was chaired by Catterina Ferreccio and Geoff Ginsburg. Those who had submitted proposals did not participate in the review. Proposals were submitted in August and reviewed via online survey tool.

There were seven submissions across a variety of topics including COVID-19. Six proposals were selected for funding (five full, one partial funding). Projects included an average of eight IHCC cohorts (ranging between three and eighteen), each project with a budget maximum of \$150,000. These projects, in addition to the ongoing IHCC pilot project on polygenic risk scores (PRS) represent nearly \$1 million of funding for cross-cohort scientific initiatives from sponsors including the USA National Institutes of Health (NIH), Wellcome Trust (WT), and Chan Zuckerberg Initiative (CZI). The IHCC Secretariat has been developing internal administrative structures for these and future awards to enable contracting within specified requirements and deliverables to IHCC sponsors. Contracts for the awards are currently being issued, to be followed by various project kick off meetings in the coming weeks.

Exploring the role of genetically determined BMI in infancy, childhood, and early adulthood on colorectal cancer development in later life – David Hughes, PhD (University College Dublin, Ireland)

This project will be co-led by Mazda Jenab (France) and Vernika Fedirko (USA) with collaborators Neil Murphy (France), Heinz Freisling (France) and a dedicated post-doc to be recruited. Global heterogeneity in cancer incidence suggests the influence of modifiable risk factors such as obesity and duration of weight gain for cancers such as colorectal cancer (CRC). There is limited evidence on the association between early life exposures such as obesity and cancer etiology by consideration of genetic predisposition. This project will examine the hypothesis that varying obesogenic inherited predisposition in early and later life stages infers different metabolic processes that may underlie adiposity and differentially impact the risk of CRC and possibly earlier onset disease, assessing whether life-course specific markers of obesity will influence the development of CRC. Specifically, they will use available IHCC cohort single nucleotide polymorphism (SNP) data to construct four specific genetic risk scores (GRS) for infancy, childhood, adulthood, and overlapping childhood-adulthood. The main research questions include:

- Do individuals with varying genetic propensity towards obesity at various life stages have different risks for CRC development in adulthood?
- Do the risks vary by (a) higher body size across the life course, compared to only in early or later life stages, and (b) exposure to obesogenic dietary and lifestyle factors in adult life?
- Are inflammation and metabolic dysfunction underlying mechanisms for these associations for CRC?

Available data for SNPs already robustly associated with obesity will be extracted to construct the GRS at each life stage and will be applied to risks for developing CRC. Other anthropometric measures will also be considered and explored along with underlying mechanisms using biomarker measurements available in a subset of the CRC cohort. This project currently includes the UK Biobank (~6,000 CRC cases with GWAS data), European Prospective Investigation of Cancer and Nutrition (EPIC) cohort (~2700 CRC cases with GWAS data, 1500 with biomarker data), and the Genetics and Epidemiology of CRC Consortium (GECCO) (52,000+ CRC cases from North America, Australia, Asia, Europe). GECCO includes contributions from several IHCC cohorts. Results of this project should inform cancer control strategies and possibly provide “windows of opportunity” for prevention of CRC and other obesity related cancers. Additional IHCC members with relevant data (GWAS or obesity related genetic association data, anthropometric measures in any life stage, and data on CRC events) are also encouraged to collaborate, particularly those with ethnic and geographic diversity.

High-Throughput metabolomic biomarker measures in diverse ancestries – Arash Etemadi, MD, PhD, MPH (National Cancer Institute, USA)

This project will be led by multiple IHCC cohort investigators: Adam Butterworth, Andre Brunoni, Arash Etemadi, and Hakon Hakonarson. Early diagnosis and intervention are key to combating the burden of

chronic diseases on the individual and health systems. However, the technologies required for early intervention are often not available to minorities and in low-resource settings. Metabolic profiling may offer a low-cost scalable option for risk prediction and prevention of many chronic diseases. The study will start with four cohorts in the pilot stage to showcase the development structure for metabolomic profiling. Five thousand samples from the South Asian Cohorts (Bangladesh), Brazilian Longitudinal Study of Adult Health (ELSA) (Brazil), Golestan Cohort Study (Iran), and the Children's Hospital of Philadelphia (USA) will be analyzed using the Nightingale Health blood biomarker platform (nuclear magnetic resonance spectroscopy). Samples will be shipped to Nightingale in November/December of 2020. Results (estimated available in March of 2021) will be combined with existing genetic and health outcome data to analyze associations and consider cohort-specific outcomes (e.g., diabetes, ischemic heart disease, autoimmune disease). Project analysis should be ready by June of 2021 with final recommendations available by September 2021. Next steps of the project might combine results with additional IHCC cohorts that also have Nightingale data (e.g., UK Biobank, Mexico City study, UI Blood Donors Cohort, Kadoorie Biobank).

Opioid cohort consortium (OPICO) to investigate the effects of regular opioid use on mortality and on cancer development – Mahdi Sheikh, MD (*International Agency for Research on Cancer*)

Opioid use leads to thousands of deaths and billions in economic losses each year, however the long-term effects of opioid use are largely unknown. Among the nearly 60 million opioid users in 2018, about half used opium products. The limited studies of users have shown associations with at least nine cancer types, genotoxicity, and carcinogenic compounds present in the opium/heroin samples. Opium consumption has been classified as a Group 1 carcinogen to humans. The remaining opioids are pharmaceutical products, which have limited data registries of users, but show some association with cancer types (e.g., lung, urogenital, liver), genotoxicity, tumor promotion, and involvement in tumor initiation and progression. Current evidence is limited due to confounding effects and limited data on usage. Patterns of use, underlying health conditions, and legislation are varied across countries and thus a consortium-based approach is needed to evaluate long-term effects of opioid use in population cohorts.

OPICO will be a resource for multidisciplinary scientific studies on the use of opioids and their long-term hazardous effects. Initial evidence from the UK Biobank and Golestan Cohort study suggest associations with overall mortality, cancer mortality, digestive disease mortality, respiratory mortality, premature death, and cardiovascular mortality. OPICO will capture exposure data from existing questionnaires and linked prescription registries and national records and evaluate outcomes such as cancer (digestive, respiratory, urinary, brain) and mortality (all cause, circulatory, respiratory, digestive, cancer). Cohorts with interest/ability to participate in OPICO include Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Cohort, EPIC, Persian Cohort, 45&Up, Parkinson Associated Risk Syndrome (PARS) Cohort, Golestan Cohort, Generation Scotland, and UK Biobank. These cohorts may include up to 70,000 opioid users. In the future, OPICO will build structures for data sharing and analysis for further genetic and biomarker studies. Additional interested cohorts with relevant data on opioid use (or medication use) are encouraged to join the project team.

Cohort Engagement – Hákon Hákonarson, MD, PhD (*Children's Hospital of Philadelphia, USA*)

The PRS Pilot project has continued since initial presentation of preliminary data at ICS3. This project aimed to demonstrate proof-of-principle for cross-cohort research on a condensed timeline (~two months). All IHCC cohorts were invited to participate in the project with a federated data model where sites were guided to generate PRS locally and share summary statistics for centralized analysis; twelve cohorts were able to participate during this brief timeline. PRS data was generated for the primary

phenotypes of body-mass index (BMI), type two diabetes, hypertension, and asthma. These were selected based on their common presentation and likelihood of access to phenotypic indicators in multiple IHCC cohorts. The project aimed to establish trans-ethnic PRS based on meta-analysis of summary statistic data. Each trait leveraged recent large scale meta-analysis reported with publicly available genome-wide summary statistics. Linkage Disequilibrium (LD) pred weights were generated using LD patterns from African, Hispanic, East Asian, Northern European, and trans-ethnic (all) populations. Participating cohorts include ELSA-Brazil, Norwegian Mother and Child Cohort Study (MoBa), Children's Hospital of Philadelphia (CHOP) Biorepository, Nurses' Health Study (NHS), Nurses' Health Study II, Shanghai Men's Health Study, Shanghai Women's Health Study, UK Blood Donor Cohorts, 23andMe, East London Genes and Health, and the Estonian Genome Project. Weight files were sent to each cohort for local computation; eight weights for the fraction of causal variants across the five ethnic groups (African American, Asian, Hispanic, European, trans-ethnic). The trans-ethnic score was more found to be more powerful for the causal variants than the specific ethnicity scores. This will be the focus of the initial publication, with an emphasis on diabetes and BMI. In addition, the project found that the modular approach to generating scores and applying across the consortium was successful. Additional population specific LD files will be useful in the future. Sharing of individual level genotypes would enable generation of common weights across all participant sites. Data use agreements were a sticking point for incorporating some data, thus the final analysis is awaiting completion while manuscript preparation is proceeding. The team aims to submit their results for publication by the end of 2020.

Another cross-cohort project has recently launched from discussions at ICS3. The Davos Alzheimer's Collaborative (DAC), established during the World Economic Forum's (WEF) 2020 Annual meeting, is co-led by WEF and the Global CEO Initiative on Alzheimer's Disease (CEOi). DAC is forming partnerships with innovative international organizations and governments to scale up emerging best practices. Since ICS3, DAC has established a project workgroup structure among various IHCC cohorts. The main objectives include creation of a Target Identification Network (TIN): a large-scale global cohort (including several IHCC cohorts) with the goal of identifying new targets for drug development and associated biomarkers. In addition, they will develop a platform to support clinical trials to reduce the time and cost of bringing new treatments to market and spur healthcare system change to deliver scientific innovation to people with AD or at risk for developing it. These main objectives should be accomplished over a five-year period. Thirty IHCC cohorts have expressed interest in participating in this project, and half of those have filled out a survey with detailed information on their cohort attributes. In addition to IHCC, DAC is also partnered with Gates Ventures. The DAC workgroups have been gathering since July 2020 to launch the pilot phase. The pilot will explore heterogeneity with regional diversity (Middle East, Southeast Asia, South America, etc.), further design the TIN and test abilities to combine and federate data for future integration of racially distinct and diverse cohorts. DAC will build a unique dataset at sufficient scale to identify patients across the world with well characterized biological samples and interoperable data to deploy and support current interventional technologies and accelerate novel technologies. The cohort will focus on preclinical stages of disease in younger age groups. For these initiatives, the UK Biobank will be a reference site for several geographically diverse IHCC cohorts with existing data. This process will identify data gaps, which will be addressed in the next phase of the pilot where additional data will be generated on key subjects in the cohort. The pilot phase will be launched in January 2021. Additional IHCC cohorts are encouraged to participate in the pilot phase with anticipation of funding for future project phases.

Summary and Next Steps – Adam Butterworth, PhD (*University of Cambridge, UK*)

The cross-cohort projects highlighted are a sampling of the potential of IHCC. As IHCC continues to grow and evolve, more cohorts with rich diversity are needed to be involved in projects and planning. Current opportunities for engagement may be to join the committees forming from the Membership Agreement and joining some of the cross-cohort projects.

SESSION 4 – IHCC STRATEGIC PLANNING WORKSHOP

CHAIR: GEOFFREY GINSBURG, MD, PHD

14:30-16:30 UTC

Review of Strategic Planning Process and Results from Day 1 – Laura Runnels, MPH (*LAR Consulting, USA*)

Strategic planning activities on day one of this virtual meeting examined both barriers and facilitators for IHCC successes. Initial review of that discussion revealed that IHCC successes including organizing a large group, securing cohort membership, fostering collaboration, engagement in a variety of activities, distributing opportunities, and communicating to members. IHCC also fell short in similar areas: communicating with members, engaging cohorts, closing gaps between LMICs and others, demonstrating value, securing funding, sharing and harmonizing data, and implementing projects. Successes were in part driven by leadership, staff, inclusivity of the group, diversity of members, sharing a common goal with group buy in, and funding. Some of the challenges stemmed from data sharing barriers, lack of clarity, meetings/projects with a standard group, and planned activities that do not accommodate needs of all cohorts. Important contextual factors were identified such as data protection laws, COVID-19 research opportunities, diversity and inclusion, technology developments, political pressures, decreasing sequencing costs, climate change, and comparable genomics organizations. Members also identified risks to IHCC such as lack of long-term core funding, challenges with trust, confidentiality, etc., value of cohort engagement, lack of a clear vision and mission, succession planning, and limited publications/papers to establish clear value.

On the second day of the strategic planning workshops, attendees were moved into breakout rooms to consider ideas for what IHCC might want to accomplish in the coming months/years. Details on outcomes of this workshop will be documented in the Strategic Planning Report, to be made available in early 2021.

Day 2 Closing Remarks – Geoffrey Ginsburg, MD, PhD (*Duke University, USA*)

Strategic planning will shape the next steps for IHCC and will be used to inform prospective funders about organization goals and initiatives. The final report will be available to members and the public in 2021. IHCC greatly benefits from the cooperation of members across the globe and is committed to regular communication and sharing of ideas in alignment with the IHCC mission and vision.

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PARTICIPATING COHORTS

23andMe

45 and Up Study

Africa Health Research Institute (AHRI) Population Cohort

Biobank Japan

Canadian Partnership for Tomorrow Project (CanPath)

Cancer Prevention Study II (CPS-II)

Cancer Prevention Study II Nutrition Cohort

Children's Hospital of Philadelphia (CHOP) Biorepository

China Kadoorie Biobank

Connect for Cancer Prevention Study

Constances Project

COVIGen-SA

Dementias Platform UK (data repository)

East London Genes and Health

ELSA-Brazil Project

Environmental Polymorphisms Registry

EPIC (European Prospective Investigation into Cancer, Chronic Diseases, Nutrition and Lifestyle)

EpiHealth

Estonian Genome Project

Generations Study (GS)

Generation Victoria (GenV)

Golestan Cohort Study

H3Africa

HUNT Study

Korea Biobank Project

Korean Cancer Prevention Study (KCPS-II Biobank)

Korean Genome and Epidemiological Study (KoGES)

Maule Cohort (MAUCO Study)

Mexico City Prospective Study

Multiethnic Cohort Study (MEC, NCI)

MyCode Community Health Initiative

National Cancer Institute (NCI) Cohort Consortium

National Israeli Cancer Control Center

Netherlands Twin Registry

Newfoundland and Labrador Genome Project

NHSII (Nurses' Health Study II, NCI)

Northern Sweden Health and Disease Study

Persian Cohort Study

Personalized Environment and Genetics Survey (PEGS)

Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial, NCI (PLCO)

Qatar Biobank Cohort

South African Population Research Infrastructure Network (SAPRIN)

Shanghai Men's Health Study

Shanghai Women's Health Study

Health for Life in Singapore (HELIOS)

South Asian Biobank

Swiss National Cohort

SYNCHROS

Tohoku Medical Megabank Project

U.S. Precision Medicine Initiative / All of Us

UK Collaborative Trial of Ovarian Cancer Screening Longitudinal Women's Cohort (UKLWC)

Women's Health Initiative (WHI)

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