



# International Hundred K+ Cohorts Consortium (IHCC)

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5th International G2MC VIRTUAL Conference

May 7, 2020

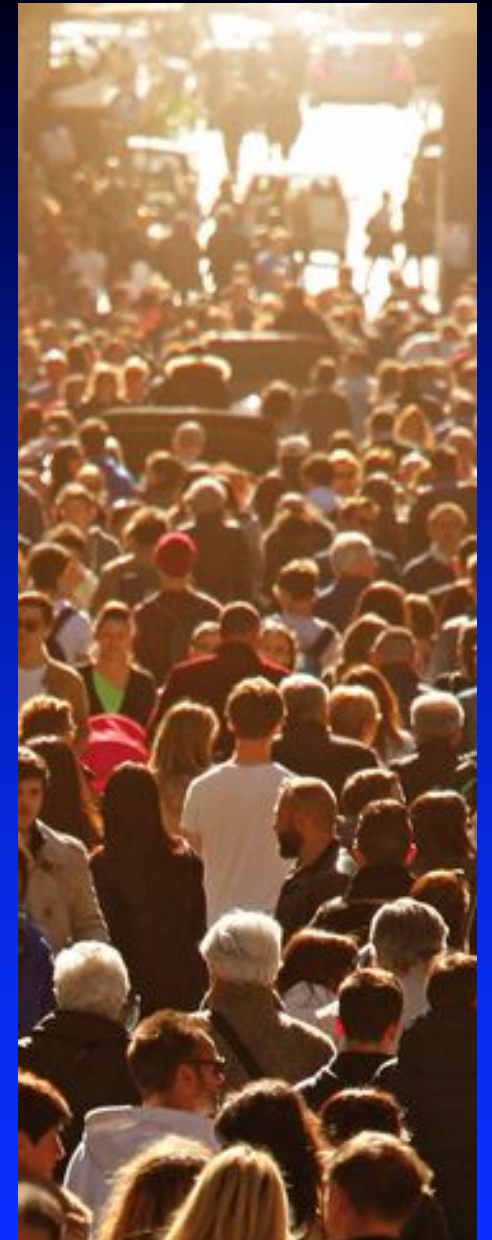


National Human Genome  
Research Institute

—  
The **Forefront**  
of **Genomics**<sup>®</sup>  
—

# IHCC: Premise

- Large cohort studies being established in several regions world-wide
- Each constrained by size, ancestral origins, and geographic boundaries
- Constraints limit subgroups, exposures, and interactions each can examine
- Combining data from these cohorts enables addressing pressing global health questions none can answer alone
  - Enhance value of each
  - Leverage enormous existing investments in them



# IHCC: Vision



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.

# Relevant History



- 2015: NIH compiled information on large cohort programs ( $\geq 100\text{K}$  participants)
- June 2017: HIROs agreed to bring cohorts together, to encourage data sharing, improve efficiencies, & maximize investments
- October 2017: G2MC Secretariat invited to identify cohorts, organize and host exploratory summit
- March 2018: First Cohorts Summit at Duke University, U.S.
- April 2019: Second Cohorts Summit in Reykjavik, Iceland
- May 2020: Third Cohorts Summit in **Virtual** Santiago, Chile

G2MC



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Collaborate. Innovate. Accelerate.

GA4GH



# International HundredK+ Cohorts Consortium (IHCC)



## International HundredK+ Cohorts Consortium (IHCC)

Linking cohorts, understanding biology, improving health



HOME

HOME

ABOUT IHCC

LEADERSHIP

MEMBER COHORTS

EVENTS

TEAMS

CONTACT US

G2MC

### Member Cohorts

Verified Members Cohorts as of October 2019

Filter Cohorts



Cohort Name	PI - Lead	Participating countries	Current Enrollment	Target Enrollment	Enrollment Period	Genomic Data	Environmental Data	Biospecimens	Phenotypic /Clinical Data	Data Sharing Potential	Member Data Verified
+ Million Women Study	Valerie Beral	England, Scotland	1,320,000		1996:2001		No	Yes	Yes	Yes	Verified
+ Qatar Genome Project	Hamdi Mbarek	Qatar	15,000	300,000	2015: ongoing			Yes	Yes		Verified
+ Shanghai Men and Women's Health Study (2 cohorts)	Wei Zheng	Shanghai, China	136,000		1996:2000		No	Yes	Yes		Verified
+ China PEACE (Patient-centered Evaluative Assessment of Cardiac Events) Million Persons Project	Linxin Jiang	China	2,000,000	4,000,000	2014:ongoing	No	Yes	Yes	Yes	Yes	Verified

# 1<sup>st</sup> International Cohorts Summit (March 2018)

## Goals:

- Explore prospects for collaboration and compatibility of cohorts
- Discuss a searchable global cohort registry
- Understand barriers to data and specimen sharing

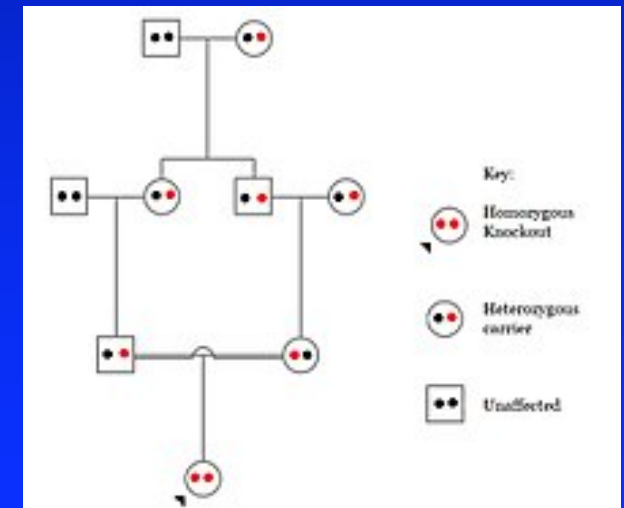
## Criteria for cohort participation:

- $\geq 100,000$  participants
- Not selected for disease
- Available biospecimens
- Potential for longitudinal follow-up



# Compelling Scientific Questions that can be Addressed with Millions of Individuals

- Risks associated with rare exposures and outcomes
- Generalizability of risk factors and associations
- Population-specific determinants of health
- Social or cultural determinants of health
- Country- or cohort-specific risk predictions
- Impact of changing environments through migrant studies
- Human knock-out identification and phenotyping



# Overarching Goals

- Develop the **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
- Develop the **policy agenda** to advance data sharing, engagement with industry





# IHCC Task Teams

## **Data Standards and Interoperability: Philip Awadalla, Thomas Keane**

Charge: Deliver IT standards and infrastructure to enable accessibility of population scale data across international borders

## **Scientific Strategy and Cohort Enhancements: Adam Butterworth, Hakon Hakonarson, Gad Rennert**

Charge: Develop scientific agenda to identify novel approaches to diagnose and treat genomic conditions, explore enhancements to existing cohorts, and address diversity gaps

## **Policy and Bio-data Sharing: GunPeggy Knudsen, Laura Rodriguez**

Charge: Develop policy agenda to facilitate and optimize impact of assembling cohorts; address challenges and identify common needs



# Second Summit (2019)

Reykjavik April 23-24



- 117 representatives of 67 cohorts from 29 countries
- 10 HIRO groups: AMED, A-STAR, BMGF, CIHR, EC, MRC, NIH, ICMR, MRC, WT
- Information technology and policy plans to support the science
- Interest in adopting a formal collaborative structure and charter
- Biopharma and sequencing tech firms to requests participate

# 3<sup>rd</sup> International Cohorts Summit

## Santiago, Chile, May 5-6, 2020



- Coalesce around visionary charter and path forward
- Introduce cohorts atlas to enable collaborations among cohorts
- Plan for development of global “tool box” of best practices, policies, methodologic approaches and data sciences
- Engage full membership in charting scientific agenda
- Identify scientifically meritorious cross-cohort research projects and international collaborators willing to organize and participate in them
- Develop IHCC scientific agenda to bring forward to funders

World Map

NEW

U.S. Map

Critical Trends

COVID-19 Dashboard by the Center for Systems Science and Engineering (CSSE) at Johns Hopkins University (JHU)

Total Confirmed 3,254,727

Confirmed Cases by Country/Region/Sovereignty

- 1,069,534 US
- 213,435 Spain
- 205,463 Italy
- 172,481 United Kingdom
- 167,299 France
- 163,009 Germany
- 120,204 Turkey
- 106,498 Russia
- 94,640 Iran
- 85,380 Brazil
- 83,950 China
- 54,455 Canada
- 48,519 Belgium

Admin0

Last Updated at (M/D/YYYY) 4/30/2020, 8:58:51 PM



Cumulative Confirmed Cases

Esri, FAO, NOAA

187 countries/regions

Lancet Inf Dis Article: Here. Mobile Version: Here. Lead by JHU CSSE. Automation Support: Esri Living Atlas team and JHU APL. Contact US. FAO.

Data sources: WHO, CDC, ECDC, NHC, DXY, 1point3acres, Worldometers.info, BNO, the COVID

Total Deaths 233,363

- 27,967 deaths Italy
- 26,771 deaths United Kingdom
- 24,543 deaths Spain
- 24,376 deaths France
- 18,069 deaths New York City New York US
- 7,594 deaths Belgium

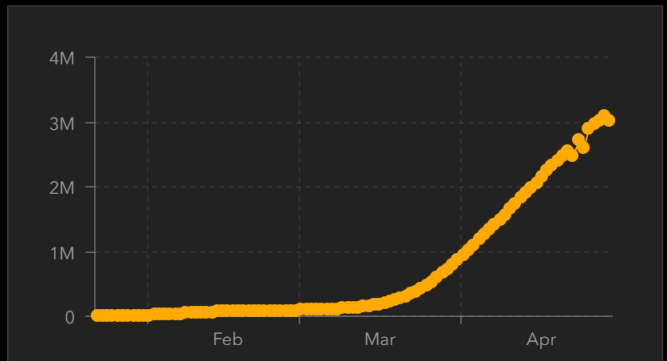
Deaths

Recovered

Total Test Results in US 6,231,182

- 900,636 tested New York US
- 625,337 tested California US
- 382,405 tested Florida US
- 314,790 tested Texas US
- 275,647 tested Massachusetts US
- 269,867 tested Illinois US

217,019 tested US total tests



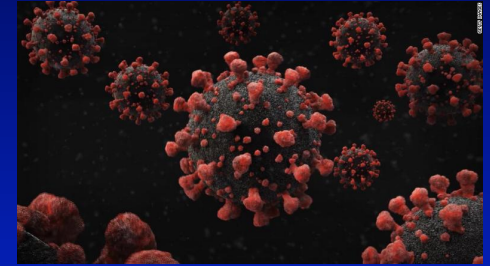
Confirmed

Logarithmic

Daily Cases

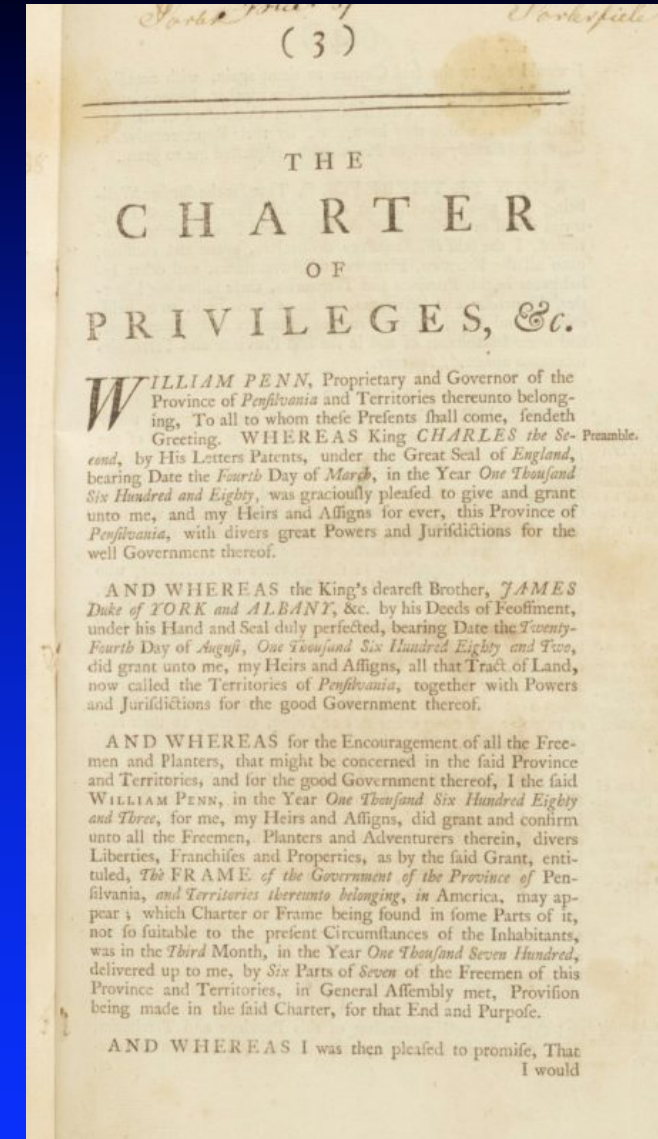
# IHCC Summit 3 Objectives

- Galvanize the IHCC around a visionary charter and path forward (defining the IHCC organization, mission, membership, partnership opportunities, industry engagement)
- Examine how IHCC can rapidly mobilize worldwide cohorts to address the COVID-19 pandemic
- Introduce the IHCC to a cohorts atlas that can be used to stimulate/enable collaborations among cohorts
- 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



# IHCC Charter, Governance, Policies

- Guiding principles: transparency, fairness, equity, inclusivity
- Living document, guidelines rather than contract
  - Requirements and expectations for collaboration
  - Governance structure
  - Membership types: affiliate and industry
- Publication policy: submit publication plan with scientific project proposal
- Collaboration with industry: avoid tobacco/nicotine, alcohol industries
- Data sharing principles: GA4GH framework



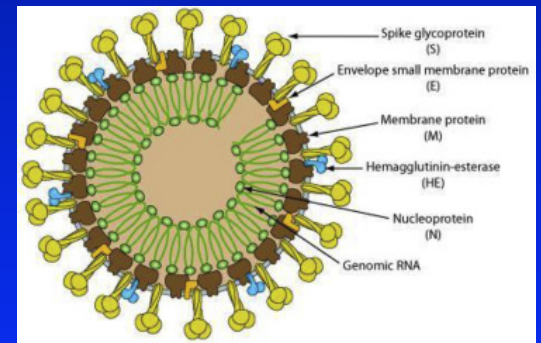
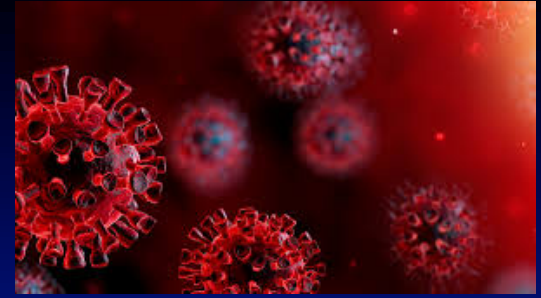
# Data and Infrastructure, Scientific Strategies

- Working prototype atlas demonstrated, search functions robust and flexible, harmonization working
- Further populate with IHCC cohorts' data
- Establish compelling set of research and clinical showcase applications
- Harmonize COVID-19 data dictionaries for cross cohort discovery and analysis
- Add COVID-19 cohort phenotyping in IHCC Atlas
- Pilot polygenic risk scores project on 4 traits with federated data launched and completed

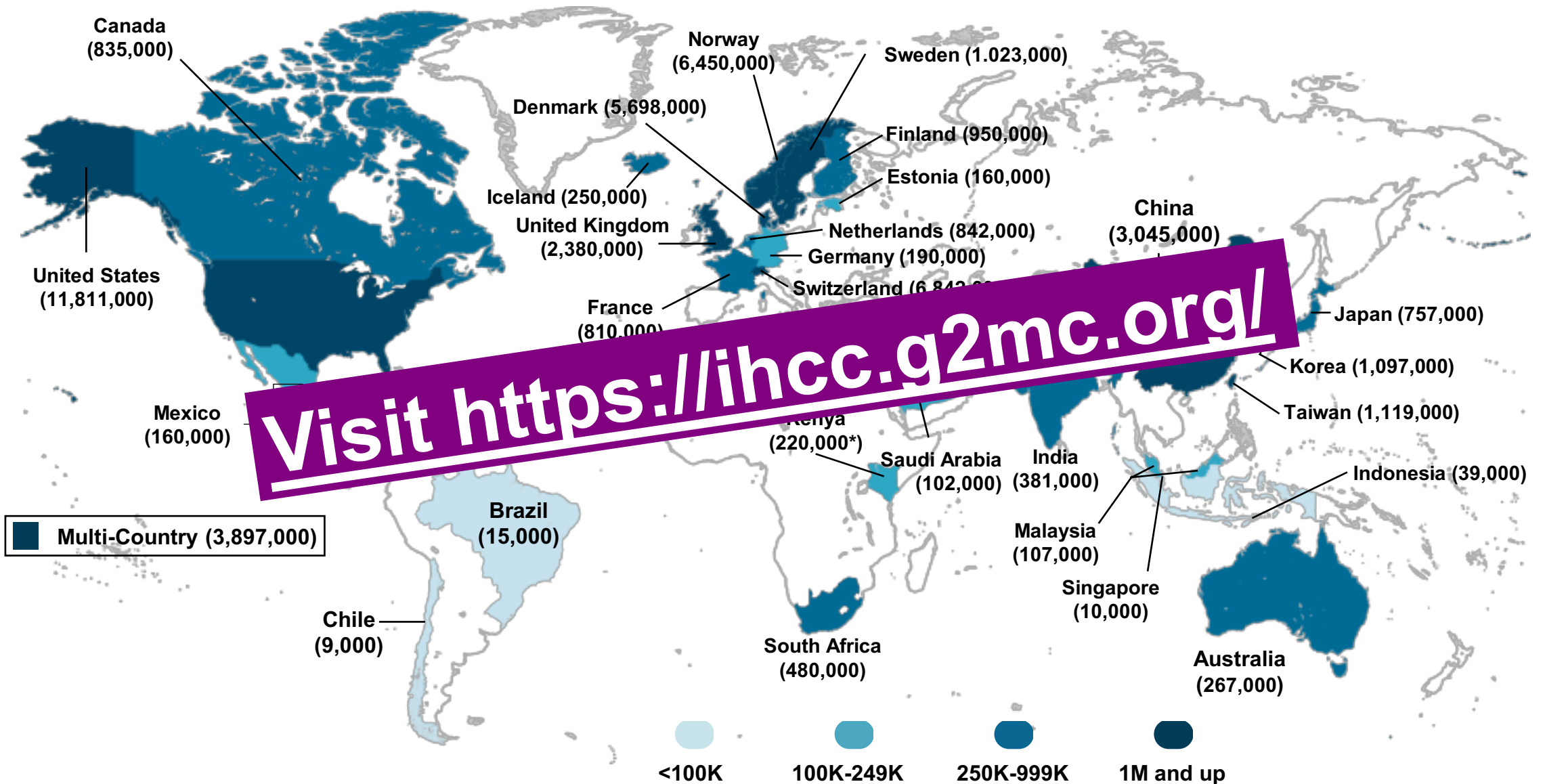


# COVID-19 Research Topics

- Global expansion and timing of COVID-19
  - Serology, timing of control/mitigation measures
- Impact of host genome and environmental exposures on COVID-19 manifestations
  - Sex differences, ethnicity, comorbidity, resilience
  - Tobacco/environmental pollution, population density/urbanization, public health infrastructure
  - Role of biomarkers in COVID-19 outcomes
- Impact on mental health/anxiety
- Biospecimen standards







**97 Cohorts, > 50M Participants**

# Many Thanks

Adam Butterworth

Zhengming Chen

John Connolly

Mary de Silva

Robert Eiss

Paul Elliott

Geoff Ginsburg

Peter Goodhand

Hakon Hakonarson

Norihiro Kato

Thomas Keane

Hannah Kennel

Gun Peggy Knudsen

Rongling Li

Eric Plummer

Gadi Rennert

Laura Rodriguez

Brittany Zick

# And 97 Cohort Leaders and Participants!

