



International Cohorts Summit

Hosted by the Global Genomic Medicine Collaborative (G2MC)

JB Duke Hotel (Ballroom ABC on Level 3, i.e. lobby level), 230 Science Dr, Durham, North Carolina, USA
March 26th-27th, 2018

Meeting Objectives

- Improve prospects for interoperability and compatibility of instruments, data formats, phenotypic and clinical measures, etc.
- Promote data sharing and open access policies
- Broaden international cooperation through existing tools and resources
- Explore the feasibility of a "digital" platform, or web-based, evolving registry of large-scale cohorts, in searchable format
- Examine the potential for a collaborative sequencing (and other -omics?) strategy
- Consider strategies for translating findings for health impact
- Advance a collective vision: where do we want to be in ten years?

Day 1, Monday, March 26

7:30 – 8:30 Registration [location: JB Duke Hotel atrium, Level 3 (i.e. lobby level)]

Session 1 – Introduction and Background

Chairs: Geoff Ginsburg & Teri Manolio

8:30 – 8:50	Welcome and Introductions Welcome from Chancellor for Health Affairs, Duke University	Geoff Ginsburg, Teri Manolio Eugene Washington
8:50 – 9:10	Vision for summit	Francis Collins, Jeremy Farrar
9:10 – 9:15	Summary of cohorts in attendance	Teri Manolio
9:15 – 9:35	Value and challenges of combining large cohorts	Rory Collins
9:35 – 9:55	Opportunities to enhance translation for discovery to health	Geoff Ginsburg
9:55 – 10:20	Discussion	
10:20 – 10:40	Break	

Session 2 – Opportunities for Collaboration Across Cohorts

Chairs: Nicola Mulder & Rory Collins

10:40 – 11:20	Obtaining phenotype and outcome data from electronic health records and digital platforms <ul style="list-style-type: none"> • US • UK • Asia 	Josh Denny Cathie Sudlow Zhengming Chen
11:20 – 11:40	Value of biospecimen collection & biobanking	Nancy Pedersen
11:40 – 12:00	Value of genomic information and how to gather it	Matt Nelson
12:00 – 12:20	Value of other -omic information and how to gather it	John Danesh
12:20 – 12:45	Discussion	
12:45 – 1:45	Lunch	

Session 3 – Opportunities for Collaboration Across Cohorts (Cont'd)

Chairs: Francis Collins & Jeremy Farrar

1:45 – 2:05	Value of environmental information and how to gather it	David Hunter
2:05 – 2:25	Value of nutritional information and how to gather it	Walter Willett
2:25 – 2:45	Working with multi-ethnic data	Sekar Kathiresan
2:45 – 3:10	Discussion	
3:10 – 3:30	Break	

Session 4 – Data Standards and Privacy

Chair: Eric Dishman & Geoff Ginsburg

3:30 – 3:50	Data standards and global variant databases	Thomas Keane
3:50 – 4:10	Informed consent, data privacy	Laura Rodriguez
4:10 – 4:30	Quantitative science to optimize the value of cohort data	Robert Califf
4:30 – 5:00	Discussion	



Session 5 – Break Out Sessions Begin

5:00 – 6:00	Working sessions, leaders, and key topics to address	
Group 1 [Boardroom A, Level 3]	Creating a standardized database and registry—pros, cons, how best to do it <ul style="list-style-type: none">• What data are cohort investigators willing to share, with whom, and how?• What challenges need to be addressed to optimize the value of sharing information?	Joyce Tung Daniel MacArthur
Group 2 [Ballroom E, Level 3]	IT considerations for enabling coordination, communication, centralization (include federated databases) <ul style="list-style-type: none">• What data are collected/available for each of your cohorts and what are their formats?• What are sources of those data (e.g. electronic health record, laboratory, radiology, genomics, proteomics, metabolomics, others)?• How are data collected in each of your cohorts stored?• How are the data distributed, accessed, made discoverable? What are the challenges to enabling federated joint cohort analysis to benefit clinicians and research discoveries?• Are there other IT considerations/challenges not covered above?	Teresa Zayas Cabán Thomas Keane
Group 3 [Meeting Room D, Level 2]	Scientific agenda with short- and long-term goals <ul style="list-style-type: none">• What enhancements to existing cohorts would most increase their utility and promote data sharing?• What are the highest priority scientific questions that could be addressed by a cohort of cohorts?	Geoff Ginsburg Rory Collins
Group 4 [Boardroom B, Level 3]	Policy agenda to facilitate and optimize impact of assembling these cohorts (include MTAs, IRBs, consent, etc) <ul style="list-style-type: none">• What specific legal or regulatory barriers in each cohort, aside from ensuring confidentiality and appropriate consent, would impede data sharing of: a) genetic information; b) demographic and clinically-relevant data? What solutions or options to work through challenges could be pursued?• What (if any) concerns might be raised by private industry involvement in a cohort of cohorts and how could they be dealt with?	Laura Rodriguez Gad Rennert



Group 5 [Ballroom ABC, Level 3]	<p>Developing a collaborative genomic sequencing (and other -omics?) strategy</p> <ul style="list-style-type: none"> • What kinds of sequencing or other -omic data would be useful for individual cohorts? • What aspects of a collaborative sequencing strategy, in addition to low cost, would facilitate obtaining and sharing these data? • What methods/tools are optimal for data harmonization across different sites to address platform diversity/uniformity, batch effects and related issues 	John Danesh Hakon Hakonarson
Group 6 [Meeting Room C, Level 2]	<p>Translation / clinical impact</p> <ul style="list-style-type: none"> • What are the opportunities for translation of cohort findings to improved clinical care and population health? • What are the major barriers to clinical and population health translation and how can they be dealt with? 	Eric Green Dan Roden
6:00	Adjourn	
6:30	Depart for dinner [meet at front entry of JB Duke Hotel for group transportation]	
7:00	Group Dinner at Mothers & Sons Restaurant	

Day 2, Tuesday, March 27

8:00 – 8:15 Opening Day 2 Geoff Ginsburg, Teri Manolio

Session 6 – EU Cohorts and Break Out Working Sessions

Chair: Andres Metspalu & Teri Manolio

8:15 – 8:45	The EU Experience in Assembling Cohorts of Cohorts	Philippe Cupers
8:45 – 9:00	Welcome from the Dean of Medicine, Duke University	Mary Klotman
9:00 – 10:00	Break Out Group Working sessions (same room assignments as Day 1)	
10:00 – 10:20	Break	



Session 7 – Break Out Reports and Discussion

Chair: Camilla Stoltenberg & Rory Collins

10:20 – 10:40	Group 1: Standardized database	Joyce Tung Daniel MacArthur
10:40 – 11:00	Group 2: IT considerations	Teresa Zayas Cabán Thomas Keane
11:00 – 11:20	Group 3: Scientific agenda	Geoff Ginsburg Rory Collins
11:20 – 11:40	Group 4: Policy agenda	Laura Rodriguez Gad Rennert
11:40 – 12:00	Group 5: Collaborative sequencing strategy	John Danesh Hakon Hakonarson
12:00 – 12:20	Group 6: Translation / clinical impact	Eric Green Dan Roden

Session 8 – Working Lunch, Summary and Next Steps

12:20 – 12:50	Lunch (pick up box lunch and return)	
12:50 – 1:35	Summary, outline of 1-year plan	Geoff Ginsburg Teri Manolio
1:35– 2:15	Consensus vision and path forward	Francis Collins Jeremy Farrar
2:15	Adjourn	