Global Genomic
Medicine Collaborative

International Cohorts Summit

Breakout Group 4

Policy agenda to facilitate and optimize impact of assembling these cohorts (include MTAs, IRBs, consent, etc.)

Common Challenges for International Collaboration Participation:

International Cohorts Summit

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1. Demonstration of Benefit to Stakeholders (Funders, Participants, Investigators, Public)
    a. How cohort research (and Collaboration) are meeting mission
    b. Impact (or potential for impact) on public health issues
2. Institutional Interpretation of Local/National Regulations
    a. Especially if need for each site within a cohort to approve participation
3. Heightened Concerns with Sample Sharing
4. Lack of Education/Understanding of IRBs, Providers, Public (Policy Makers)
5. Data Access Framework
    a. Many cohorts established as local enclaves or with cohort-specific use reviews, need to consider how to integrate this into Collaboration governance
    b. Potential uses limited to ‘lowest common denominator’
6. Inclusion/Management of Data Generated in Native & Aboriginal Populations and the Communities’ Perspectives

Common Needs/Potential Benefits for Collaboration Participation:

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1. Define What the “It” is for the Collaboration
   a. Joint policy and scientific design discussion for Collaboration or initiatives
2. Clear Distillation of Collaborations’ Guiding Principles and Goals
   a. Define ‘what’s in it’ for cohorts (and their participants) so potential benefits are clear and concerns mediated
   b. Perhaps develop a common use statement that could define basic Collaboration participation
   c. Consider including what will not be part of Collaboration (e.g., prohibited uses)
3. Development of International Principles to Inform Local/National Decision-making
   a. Potential to inform future policy making
   b. Provide language to address international collaboration (e.g., for use in informed consent processes or re-contact/re-consent)
   c. Inclusion of For-profit entities in activities, e.g., expectations related to reciprocity for data sharing, or other benefits back to the collective
4. Ability to Make Choices for Participation (at cohort level, individual participant?)
   a. Develop protocol for ‘project’ review (similar to PI use/access review)

Common Needs/Potential Benefits for Collaboration Participation:

4. Ability to Make Choices for Participation (at cohort level, individual participant?)
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5. Funding Sources to Support Participation in Data Sharing (e.g., data set prep)
6. Communication Strategies & Tools to Educate Stakeholders (generally and about Collaboration)
    a. Combat misinformation, fear, lack of understanding/awareness
    b. Need for simple, clean messages (avoid the nuance)
7. Resource/Platform to Share Lessons Learned/Strategies to Overcome Barriers (e.g., successful collaborative frameworks, legislation fix for pathology samples)

Identify Actions or Pilot Efforts/Proof of Principle to Consider for Follow-up Over Next 1-3 years

1. Governance Description – Dependent on the “It” question
    a. May need an overarching description of high-level principles and priorities and separate governance frameworks for specific initiatives in early stages (e.g., proof of principle pilots)
2. Cohort Policy “traits” added to Survey of Cohort Information
    a. Enable analysis to identify potential commonalities, where accommodations are needed, and options for early vs. longer-term “phasing” collaborative efforts
        I. Legal/regulatory and funding needs
        II. Current collaborations – web of existing collaborations (case studies)
        III. Lessons learned in international sharing, collaborative structures, policy solutions, etc.
3. Develop understanding/attempt to influence of GDPR guidelines and implications for international research
4. Engaging with primary funders of cohorts to query (and build) support for shared benefit and power potentially gained by bringing efforts together