Complexities with Community Engagement
An Overview of the H3Africa CE experiences

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H3Africa

• >$76 million
• 26 projects
• 27 African countries
• >500 investigators
• Up to 75,000 research participants

Acknowledgement: H3Africa Consortium. For more information: http://h3africa.org
Nature of H3Africa projects

- Disease specific genomic studies
  - Stroke, Cardiometabolic diseases, Cervical cancer, Diabetes, Trypanosomiasis, Schizophrenia, Rheumatic heart disease,

- Multi–centre, multicounty, multiple researchers, research institutions
  - Different levels of relationships
  - Different interests
  - Different target communities

- Community–based, hospital/clinic based

- Urban communities, rural communities

- Sample collection for primary research and contribution to biorepositories
  - Broad consent, sample and data sharing
  - Limited regulatory frameworks in Africa
The complexities

- Genomic research is complex by nature
  - Not just about individuals but families and communities as well

- Growing but limited understanding of genomics and biobanking
  - Novel
  - Lay understanding of human heredity and health difficult

- Collaborative by nature involving different partners with different and sometimes competing interests

- Cultural sensitivities around blood sampling

- Samples and data collected not just for primary research but also secondary use

- Limited ethics and regulatory frameworks for genomics and biobanking in Africa
Consortium–wide engagement

1. Ethics and CE support for the consortium
2. Guidelines for researchers (Informed Consent and CE)
3. Ethics Consultation Meetings: African RECs and Policy Makers
4. Empirical Research: Broad consent_Seeley, Parker et al
5. Engaging with the academic community (publications, scientific presentations, membership of thinktanks etc)

Embedded in scientific projects

Funded ELSI projects
- Consent, community engagement, literacy in genomics, translations, stigma
Different aims of engagement

- Provide/exchange information about research with target community
- Create awareness, Educate and Mobilise the community for research
- Promote health and research literacy
- Built trust and get community buy-in and support for research
- Consult specific ‘communities’ on aspects of the research project
  - Broad consent, data and sample sharing
- Involvement?
- Collaboration?
  - What engagement beyond sample collection and establishment of biobank?
Target ‘communities’

- Participants/patients/families
- Community representatives (Village Chiefs and elders)
- Researchers
- Hospital staff
- Women groups
- Community advisory boards/patient advocacy groups
- Populations in specific geographic settings
- Research ethics committees
- Schools
- Policy makers
Engagement Approaches (H3A)

- Community meetings
- Radio and television appearance
- Community representatives
- Community advisory board (CABs)
- Patient advocacy groups
- Theatre/ Drama

- Information leaflets
- Comic books
- Pamphlets on genomics and biobanking
- Internet–based platform and mobile app
- Social media (Facebook)
- Video on biobanking
Other CE challenges

- Defining the target community
  - Who to include beyond individual sample donors
  - Who defines the community? Researchers? Communities?

- Identifying the ‘best’ methods for engagements

- Meeting community expectations

- Cost/dedicated budget

- How do we know what works?

- Lack of dedicated CE staff
Summary Thoughts

- CE in genomics is complex; different communities with different interests

- Evolving understanding of the role of CE in genomics
  - CE as an afterthought to CE as an integral part of the research
  - Funding requirements

- Anticipating and Overcoming challenges

- Evaluation remains a challenge given complexities with the nature of the H3A projects
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