

# Complexities with Community Engagement An Overview of the H3Africa CE experiences

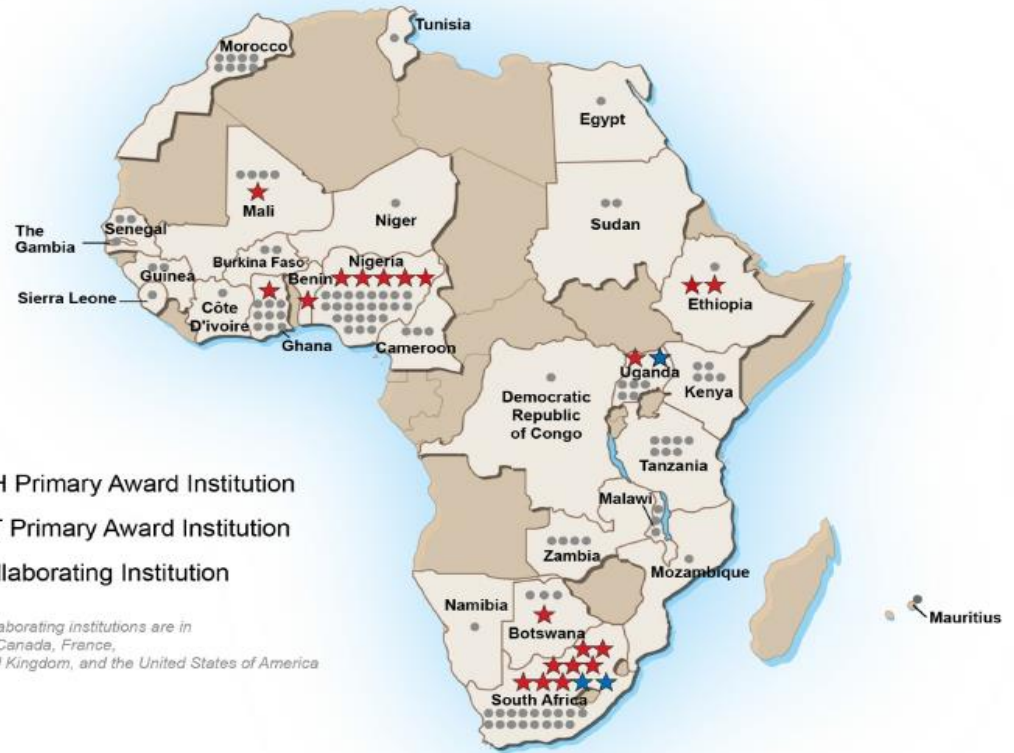
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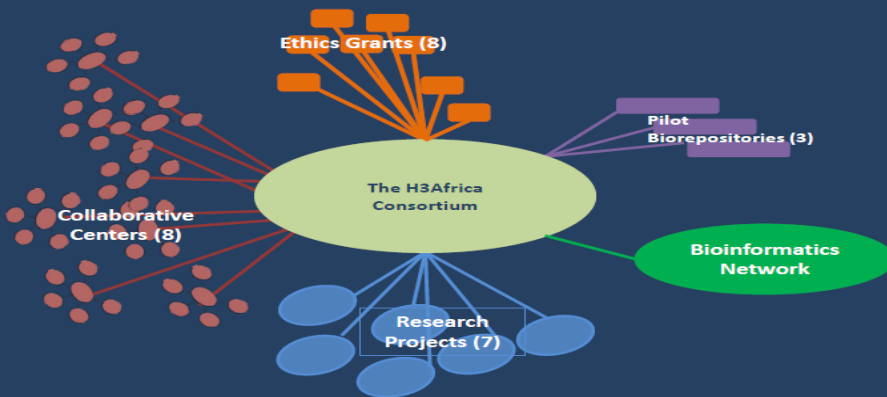
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# H3Africa

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



## The H3Africa Consortium



Acknowledgement: H3Africa Consortium. For more information: <http://h3africa.org>

# Nature of H3Africa projects

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- 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

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- 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

# Ethics and Engagement at H3Africa

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- **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

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- 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

## National Institutes of Health Wellcome Trust H3Africa Research Network





# Engagement Approaches (H3A)

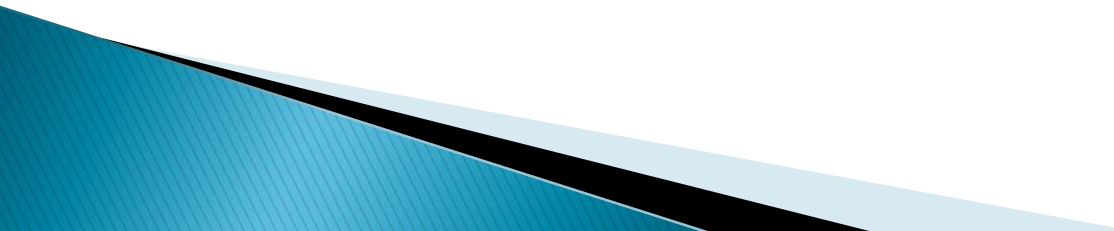
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- Community meetings
  - Radio and television appearance
  - Community representatives
  - Community advisory board (CABs)
  - Patient advocacy groups
  - Theatre/ Drama
  - Information leaflets
  - Comic books
  - Pamphlets on genomics and biobanking
  - Internet-based platform and mobile app
  - Social media (Facebook)
  - Video on biobanking
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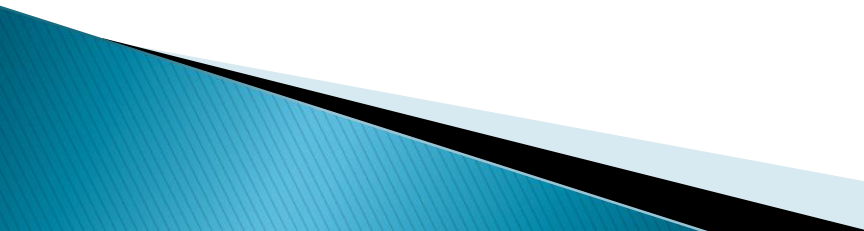
# Other CE challenges

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- 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
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# Summary Thoughts

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- 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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# Acknowledgements

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- The H3Africa Consortium
- Working Groups on Ethics and Community Engagement
- Navrongo Health Research Centre
- The Wellcome Trust and the National Institutes of Health

