TrypanoGEN:
Engaging Communities in Genetics & Genomics of HAT - Progress & Challenges

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TrypanoGEN:

To identify genetic determinants of susceptibility to Human African Trypanosomiasis (HAT)

Research Question and Objectives

Question:

What are the human genetic determinants of disease susceptibility or trypano-tolerance?

Objectives

•To create an extensive biobank of both retrospective and prospective samples with standardised parasitological and clinical metadata

•To generate a database of human genetic variation from Uganda, Zambia, Malawi, DRC, Cameroon, Cote d'Ivoire, Guinea & Burkina Faso

- So as to identify loci associated with HAT susceptibility

Risk Factors for HAT infection

- HAT is endemic in rural areas in Africa - environment
- Endemic villages: behavioural and occupational risk factors

Strong risk factors for infection:

- having a family member with a history of HAT
- proximity of a homestead to a nearby wetland area

Zoller et al. (2008) BMC 8:88

CE Objectives

1. Provide information about
   - HAT transmission – tsetse flies transmit trypanosomes
   - Risk factors for HAT – environmental, occupational and genetic
   - The need to report to hospital early – infection is suspected

2. Provide information about the current project
   - To determine why some people get infected and others do not - looking at our genetic/genomic differences

Target Communities - Science Education

1. All people living in sleeping sickness endemic areas
   - District Administrators - Secondary school
   - Health workers - University degree, diploma
   - Religious leaders - Secondary school certificate
   - Village health volunteers - Secondary school
   - Local Community - the primary target group - Secondary/primary school certificate/None

2. All people involved in HAT control
   - HAT Control Program (Ministry of Health) - University degree
   - COCTU - Coordination Office for control of Trypanosomiasis in Uganda – University degree

Communication Channels

- Interpersonal meetings (One-to-one or upto 5 people)
  - Local Authorities
  - Health workers
  - Religious leaders
  - Village health volunteers

- Public seminars – University/research community, press, interest groups

- Public meeting – Local community based meetings

- Press releases – Radio and TV

Challenges in 2000

- Ethnic and language diversity – interpretation of key words
- Rare/No genomic studies on African populations
- Lagged in genomic revolution
- Fragmented efforts

Leap-frogging into the 21st Century

- The Genomic revolution
  - Whole genome sequencing – parasite, vector and host/human
  - Genetic engineering - parasite and vector

- Initiatives exploring African Genetic Diversity in Health and Disease
  - The African Society of Human Genetics (AfSHG)
  - H3Africa – various networks
  - African genome variation project (Sanger Institute)
  - MalariaGEN
  - Biobank cohort building Network (BcNet)
  - Bridging Biobanking & Biomedical research across Africa & Europe (B3Africa)

Concerted efforts to engage with communities in biomedical research

Challenges

- Genetic & Genomic Literacy

  - Health care workers, general public – limited or lacking
  - Interpretation of genetic & genomic results – healthy or not, but at risk?
  - Communication with community in genetic/genomic terminology – an obstacle: some thoughts
    - Too technical, limited value right now and requires going back to school
    - Relationship between parasite, vector and human genes was complicated
    - No clear inheritance pattern of susceptibility to infection in families

What about informed consent?

- Genetics and Genomics:
  - Difficult concepts that take so much time to comprehend
  - Lack of “equivalent words” in local languages – make descriptions

  - Discussions focus on immediate health needs & wider community needs
    - Supply of better drugs, equipment in the diagnostic lab, community projects

- BaseLine:
  - “Understand” the purpose of the project and willing to participate

Challenges

- Medical Genetics
  - No medical genetic clinics in Uganda
  - Differentiating between clinical and genetic/genomic results vs health condition
- Genetic Counsellors
  - Few or non existent - especially in rural areas

Challenges

- Research vs medical care
  - Community expects delivery of better medicines and health care by researchers rather than medical workers

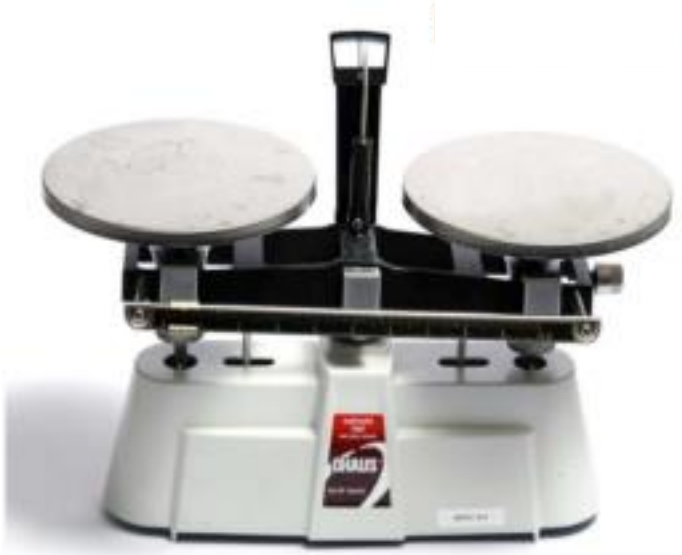
- Translation takes time:

  - To distinguish genetic variants that are truly clinically actionable
    - variants useful for guiding clinical decisions regarding interventions to improve health outcomes

- Research findings do not immediately equate to changes in clinical options

Feed back – a balancing activity!

- How and When?
- What to feed back? No incidentals, no variants identified
- To who? – individuals, families, communities?



There is hope!

Scientific Community Engagement

- Collaborations: US/Europe - Africa
  - Study diseases in natural settings working with endemic scientist
  - Training and mutual learning with novel goals
  - Fast advances in technology create new research opportunities

Possible Solutions – the good side

- There is interest in learning
  - inheritable characteristics & susceptibility to HAT
- Local Authorities are supportive of studies
- Communities are supportive of research

Capacity Building

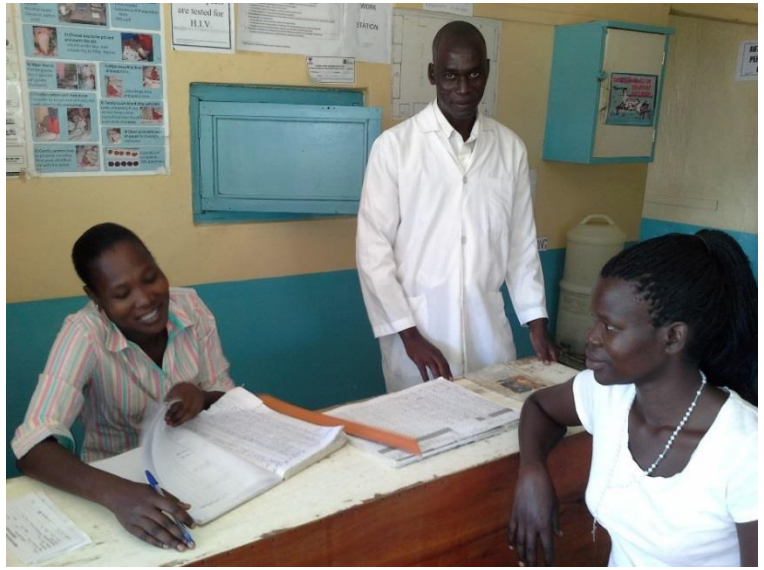
- Curriculum Review
  - Incorporate genetic and genomic approaches into biological science curriculum in training institutions – health, agriculture, etc
  - Improve basic knowledge in genetic testing, risk assessment and genetic counselling
  - Encourage science days where specialists meet students and the general public
- Establish regional genetic testing labs/clinics - long term

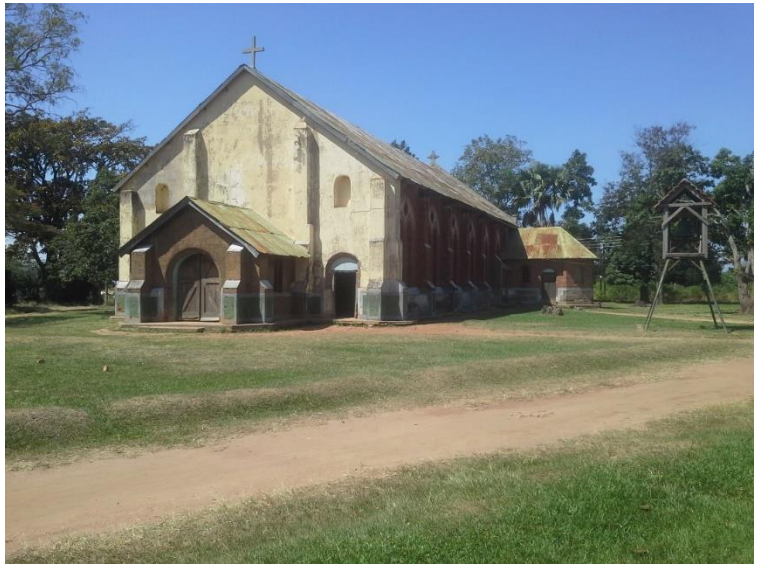
Advocacy

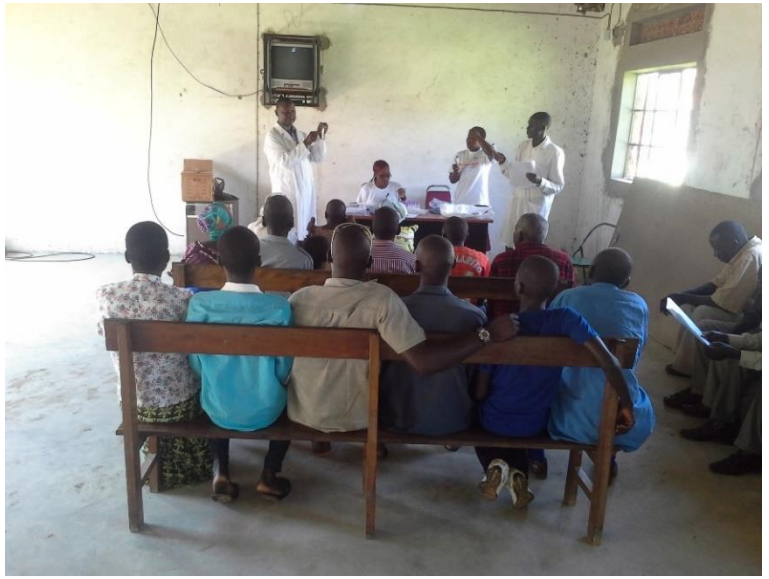
- Community and Health activists may play a role in transmitting simplified information and designing genetic and genomic literacy material

- Professionals and lay persons in IRBs are exposed to the age of genetics and genomics – transmission & interpretation

Acknowledgments







All the Communities we have worked with and continue to work with

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