Harnessing routinely collected data for human and planetary health in Uganda

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Information Rich, Data Poor

• The world is information rich
  • Routine clinical records
  • Geographic maps
  • News
  • Social media
  • Flight, shipping, transportation data
  • 2.5 quintillion bytes of data per day
    • Average USB 16 GB

• Our ability to capture this information is poor
  • Paper records
  • Unshared/uncirculated/destroyed
  • Information silos

• Our ability to harness it as useable data is even worse
  • Making sense of clinical/biological data
  • Combining different data sources
  • Having the skills to work with different data types
  • Knowing what other have
Uganda

Population: 42.8 million
GNI per capita: $620 (2018)

~30+ different languages
Official national languages: English/ Swahili

Life expectancy: 53.45 years
  1991: ~15-20% HIV prevalence (LE: ~45 yrs)
  2018: 5.7% HIV prevalence

Rich history
  Kingdoms: Buganda, Toro, Ankole, Busoga
  Empires: Kitara, Bunyoro-Kitara

British colony ‘protectorate’ 1894-1962
Military dictatorships: 1962-1986
President Yoweri Museveni 1986- present

Statistical composite of life expectancy, education & income
Geography and Conservation in Uganda

- Equatorial
- Temperate (25-29C), night lows Dec-Feb (17-18C)
- 1000-1500mm rain annually
  - Cambridge 568mm & California 544mm
  - Mawsynram, India 11,862mm & Atacama Desert, Chile 1-3mm
  - WW Average 990mmm

- Uganda Wildlife Authority
  - 10 National Parks
  - 12 wildlife preserves
  - 5 community wildlife management areas
  - 13 wildlife sanctuaries

- Party to a number of environmental agreements
  - Agreement on the Conservation of African-Eurasian Migratory Waterbirds
  - United Nations Framework Convention on Climate Change
  - Kyoto Protocol to the United Nations Framework Convention on Climate Change
  - Convention on International Trade in Endangered Species of Wild Fauna and Flora
  - Convention on Biological Diversity
  - United Nations Convention to Combat Desertification in Those Countries Experiencing Serious Drought and/or Desertification, Particularly in Africa
  - International Plant Protection Convention
  - Convention on Wetlands of International Importance, especially as Waterfowl Habitat
Geographic Tensions in Uganda

Natural Resources
- Tourism – mostly linked to wildlife parks
- Copper
- Cobalt
- Hydropower
- Arable land
- Gold

Environmental Issues
- Draining of wetlands for agricultural use
- Deforestation (~14% forest cover)
- Overgrazing
- Soil Erosion
- Biological contamination of fresh water
- Poaching
Leading Human Health Issues in Uganda

- HIV/AIDS
- Tuberculosis
- Respiratory diseases
- Diarrhoeal diseases
- Epidemic-prone diseases
- Vaccine-preventable diseases
- Malaria
Harnessing Data to Enable Health

• Surveillance is the cornerstone of public health
  • Planning
  • Understanding depth of problem

• Near real-time surveillance
  • Enables acute response interventions

• Multi-layer near real-time surveillance
  • Understanding of causes and proximal causes of a public health condition
  • Supports interventions
  • Enables novel intervention development
Harnessing Data to Enable Health

- **Point of Care Health Data**
  - Enabled by simple electronic health records & mobile technologies

- **Climate, Geographic & Other Environmental Data**

**Data Server with Automated Processing**

- Near real-time alerts for intervention deployment
- Evaluation of current intervention efficacy
- Comparison of efficacy of different interventions
- Greater understanding of causal and proximal factors
  - Novel interventions
Our Aims

• Project: Assessing the Potential for Transforming Health in Uganda through an Electronic Health Data Sharing Platform and Data Science

• Phase I
  • “Needs Assessment”
    • (a) readiness
    • (b) costs/ sustainability
    • (c) buy in
    • (d) capacity
    • (e) barriers & facilitators
  • Plan

• Phase II
  • Procurement & Implementation
Conceptual Framework for Phase I

Requirements for Effective Surveillance & Data Processing Platform

Timeliness
Information can be processed and disseminated in near real time

Capability
Infrastructures exist to enable constant functioning of the system

Costs, partners & recovery:
- Identify implementation costs and possible sources of funding
- Determine ongoing costs
- Establish cost recovery models for sustainability
- Identify cost sharing partners
- Identify donors (e.g., network charges, data collection personnel, etc.)

Sustainability
The system has built in financial recoupment to continue indefinitely

Buy-in
All parties involved and those the system serves are willing participants

Technical, ethical, governance and workforce requirements:
- What are the technical infrastructure needs, e.g., hardware, software, network connections
- Establish ethical/governance framework based on a wide range of stakeholder and national/international standards
- Determine workforce requirements and how to rapidly develop

Key stakeholder support:
- Public standards for acceptable use of health data
- What are healthcare professionals able and willing to support
- Meeting the needs of health partners, NGOs, healthcare facilities, health ministries and researchers
- Effective and efficient use of information by public health and healthcare agencies
Literature Review

• What theoretical frameworks exist/ have been developed to support implementation of eHealth programmes in low and middle income countries (LIMCs)?

• What eHealth initiatives for
  (a) data capture against public health, social, or clinical care and
  (b) interventions in public health, social and medical care have been undertaken in LMICs?

Three part search
1) Theoretical framework works
2) Data/data capture
3) Interventions

3262 Articles
Healthcare Facility Questionnaires

• All healthcare facilities are registered to a master facilities list in Uganda
  • Currently 7159

• Electronic Survey inviting 100% to participate
  • 43-items
  • Programmed in Survey Monkey
  • Background information
    • Clinic number
    • Number of health professionals
    • Population served
    • Top health concerns
  • Clinical data collection
    • When, where, how and by whom
  • Data Utilisation
  • Future Interests
Qualitative Interviews

• 200 healthcare facilities
  • Health Clinic II, III, IV and hospitals
  • Range of healthcare professionals
  • Private for profit and not for profit

• 100 Village Health Team (VHT) members & Community Health and Education Workers (CHEWs)

• Focus – three aims
  • What information they will/can collect
  • Barriers and facilitators to real-time electronic data collection
  • What information would help their practice
Focus Groups

• Six key stakeholder groups
  • the general public
  • governmental organisations
  • non-governmental organisations
  • commercial organisations
  • Researchers
  • frontline care providers

• Across all four regions stratified by low, medium and high malaria prevalence

• Objectives
  
  (a) have a thorough understanding of key stakeholder needs, support and concerns;

  (b) develop a deeper understanding partnership opportunity with key stakeholders;

  (c) identify any cost sharing or contribution opportunities; 
  
  (d) determine interest and support for the proposed models.
Information Synthesis

Quantitative & Qualitative Questionnaire

Model Systems

Infrastructure & Costs

Systematic Review

Phase II: Implementation
Supporting Human & Planetary Health in Uganda
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