Business models for sustaining biomedical databases

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What is the ReSeqTB platform?

A standardized, collated and integrated **TB genomic sequencing database** with correlated information on **phenotypic** drug susceptibility testing and **clinical outcomes**

- Develop **new diagnostics** and **treatment** regimens
- Guide **clinical decisions** and **patient management**
- Improve **global surveillance** of drug resistance
- Deliver **patient impact**

**Features**
- Easy-to-use, **cloud-based** solution
- User can **upload and store data securely** in the cloud or locally
- **Bioinformatic tools** support the user in **compliant** and **standardized** analysis and reporting
Why are we concerned about database sustainability?

• Sustaining databases is a known challenge
  • Costs for data annotation, updates, quality, data security, robust analytics, standardized reporting, hosting, support, ease-of-use and overall user experience
  • Curated knowledge with established value can become inaccessible overnight due to proprietary restrictions or database demise
  • Donors increasingly want to see a clear sustainability plan
• Challenge intensifies with global health databases – TB
  • Multiple stakeholders
  • Limited budgets
  • Mix of payers and economic levels
  • Context
Our approach

A **business model** approach to address sustainability of global health databases – ReSeqTB

- Secure funding
- Reduce costs & improve efficiencies
- Reduce risks
- Increase access and utility for multiple stakeholders

*Essentially, all models are wrong, but some are useful*

- George E.P. Box
Applying a Lean Business Model Canvas approach

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*Business Model Canvas based on Strategyzer.com*
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Select databases and resources investigated
Major Business Model options to consider

BM #1: Philanthropic Funding
Grants from private philanthropic organizations

BM #2: Government Grants
Grants from federal government entities

BM #3: Usage Fees
Freemium model for usage of database

BM #4: Partnering
Partnering with entities that can share costs & funding

BM #5: Corporate Sponsorships
Corporate partnerships seeking gifts and grants

BM #6: Hybrid Model
Combination or evolution of above models

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Next steps

- Assess and **quick-test viability** of different funding options
  - Select **interviews** with external sources
    - Beneficiaries – researchers, Dx developers, pharma, country NTPs
    - Intended partners – technical, cost-sharing, endorsement, advocacy
    - Target funding sources
  - Detailed breakdown of one-time and recurring **costs**
- Build and strengthen the overall value offering – **product management**
- Explore **governance** and **operating** structure options
  - New **non-profit entity**
  - Board of Directors – beneficiaries, **patient** and **country** representation
  - Expert **advisory panel** for regular review of status, challenges and progress
Techniques to increase odds of sustainability

- Establish a clear **value proposition** for each user group served
- Create **economies of scale**
  - Partner or merge with other entities – joint funding, data-sharing
  - Reduce developmental costs – Amazon AWS & Google for nonprofits
  - Increase efficiencies – infectious disease, HIV, AMR
- Consistently **engage user community** at all levels – **network effect**
- Seek **endorsement** from global, regulatory bodies
- Establish optimal **governance** and **operating structure**
- Assess corporate funding options – **licensing vs. giving**
- Consider **hybrid business models** – evolve to scale
- Seek **support service** – Phoenix Bioinformatics [www.phoenixbioinformatics.org](http://www.phoenixbioinformatics.org)
  - Nonprofit umbrella for orphaned biological databases

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Public health data and private entities: proceed with caution

Google DeepMind and healthcare in an age of algorithms

Julia Powles 1, 2 - Hal Hodson 1, 2

Google DeepMind's NHS data deal under scrutiny ... slammed over lack of ‘transparency’

DeepMind plans rebuttal with its own analysis

- BBC News, 17 March 2017

- Lack of clarity and transparency of purpose and means
- Issues of privacy and ownership
- Failure on both sides to engage patients and community
- Limited engagement of policymakers and regulators
- Public sector and public need to see the value of data only they can create
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