Business models for sustaining biomedical databases

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Anita Suresh

McGill International TB Centre

McGill University

What is the ReSeqTB platform?

ReSeqTB
Relational Sequencing TB Data Platform

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

Researcher | Diagnostics developer | Drug developer | Clir

World Health Organization

FIND

Critical Path to TB Drug Regimens

Stop TB Partnership
New Diagnostics Working Group

- 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

ReSeqTB
Relational Sequencing TB Data Platform

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Critical Path to TB Drug Regimens

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

Mission Statement				
Problem	Solution	Value Proposition	Beneficiaries	Donors
Existing alternatives	Key Metrics	Unfair advantage	Partners	
Budget & major cost drivers		Income & sources – donor funds & income-generating activities		

Business Model Canvas based on Strategyzer.com

Applying a Lean Business Model Canvas approach

Mission Statement				
Problem 1	Solution	Value Proposition	**Beneficiaries**	**Donors**
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Select databases and resources investigated

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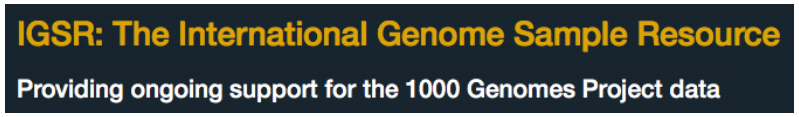


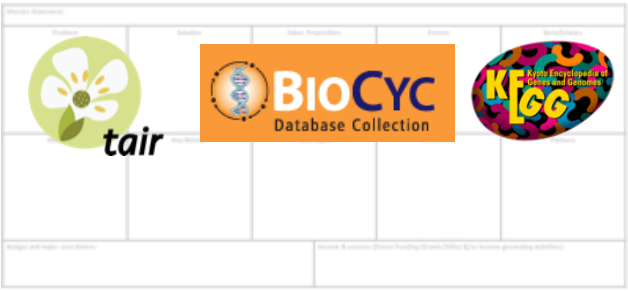
Major Business Model options to consider

BM #1: Philanthropic Funding Grants from private philanthropic organizations

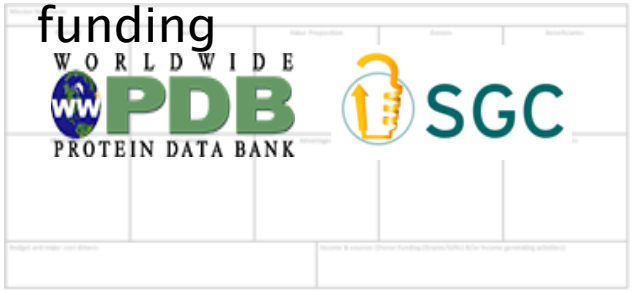
BM #2: Government Grants Grants from federal government entities

2a: Government-run

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

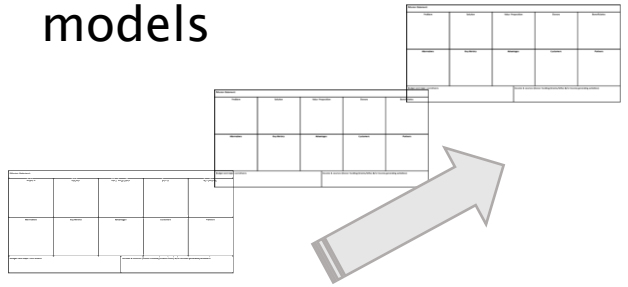


BM #4: Partnering Partnering with entities that can share costs & funding



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

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



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
  - Nonprofit umbrella for orphaned biological databases

Public health data and private entities: proceed with caution

Health Technol.
DOI 10.1007/s12553-017-0179-1

ORIGINAL PAPER

Google DeepMind and healthcare in an age of algorithms

Julia Powles[1] · Hal Hodson[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

Acknowledgements

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Anita Suresh
Global Health Business Manager
Pai TB Group, McGill University
anita.suresh@mail.mcgill.ca
Twitter: @mitokondrion