Determining the Framework of a Primary Care Based Biobank

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Background

Primary Care

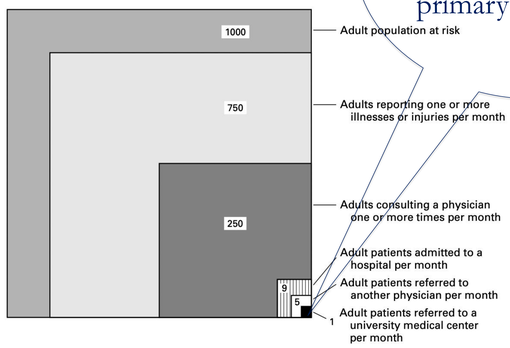


Figure 1. Monthly Prevalence Estimates of Illness in the Community and the Roles of Physicians, Hospitals, and University Medical

Canada PHAo. How Healthy are Canadians? A trend analysis of the health of Canadians from a healthy living and chronic disease perspective. 2017.

"Only 1% of the population see in a primary care care"

Research in Primary Care

Current focus and investments in health research has been put towards public education

Studies have focused on the prevalence of certain chronic diseases within specific small communities

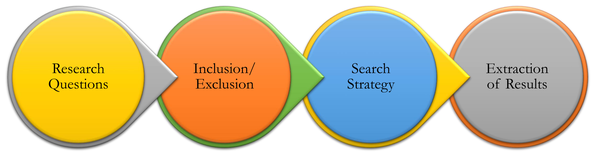
Processes leading to chronic diseases are less known

Objective

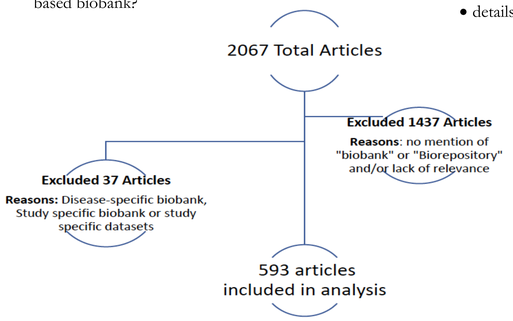
Explore the current best practices for structure and procedures associated with a disease-specific biobank and determine how this might differ for the infrastructure requirements of a primary care based biobank

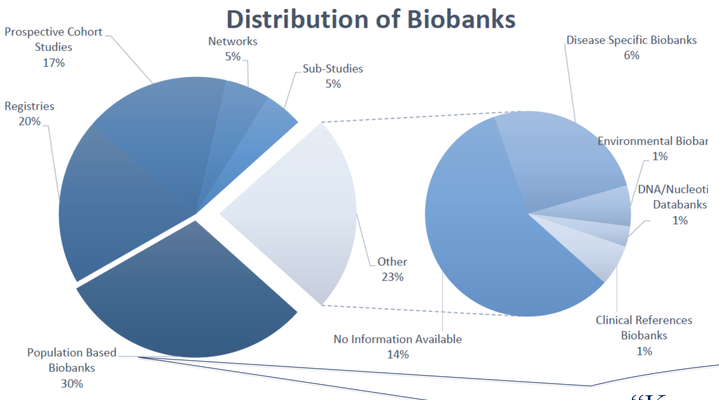
Methods

1. Narrative Review



- What is a population based biobank? What type of structure, governance, framework and policies make up a population based biobank?
- French or English only
- 1998 and 2018
- PubMed
- Geographic location (not excluded)
- Pubmed
- Analysis of the text words contained in the title and abstract of retrieved papers
- Author(s)
- Year of publication
- Origin/country of origin (where the study was published or conducted)
- details





Implication

- follow up will be key to identifying risk factors for disease and poor health outcomes
- missing a large amount of clinical, psycho-social data as well as physician interactions in primary care
- the challenge is to develop "real world" research that can capture some of the complexities seen in this context

"Key conclusions from our narrative review and their implications on primary care based biobanks"

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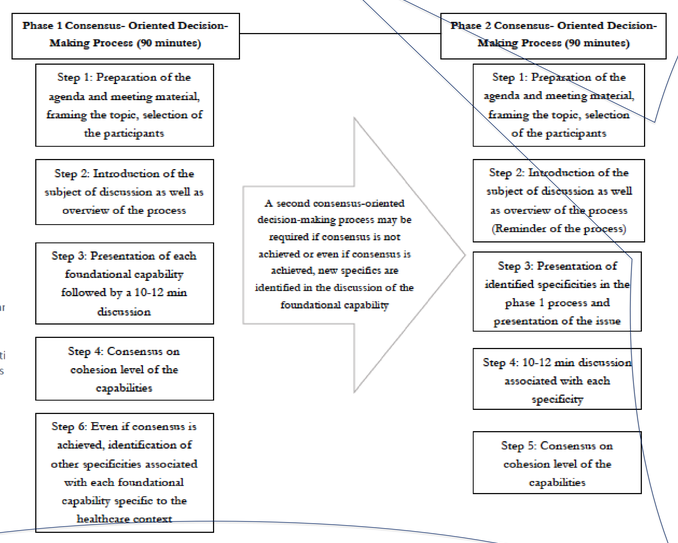
2. Consensus-Oriented Decision-Making Process (CODM)



"Consensus was sought to determine where these capabilities be set in the cohesion spectrum (referred to as a measure of connectedness and togetherness among actors within a network)".

"How can you use a consensus- oriented decision-making process to ensure stakeholder perspectives? . When setting up policies associated with a biobank, you need to make sure it fulfills responds to needs but respects the environment in which a technology is integrated"

Recruited 4 participants for the CODM

- GMF practicing physician
- Researcher from the Department of Family Medicine
- Biobank Expert
- Health Policy Researcher

Table 3a: Biobank Strategy and Governance

	Unanimous decision (# of participant)	Split decision (# of participant)
Information on biospecimen/data roadmap	Standardized (4)	-
Biospecimen/data governance model	-	- Standardized (1) - Standardized & Harmonised (3)
Operational governance model	-	- Coordinated (1) - Standardised & Harmonised (3)
Risk management	Standardized (4)	-

Table 3b: Biobank Policies and Processes

	Unanimous decision (# of participant)	Split decision (# of participant)
Privacy policies and processes	Standardized (4)	-
Security policies and processes	Standardized (3) *	-
Data/Biospecimen lifecycle policies and processes	-	- Standardised & Harmonised (4)

	Unanimous decision (# of participant)	Split decision (# of participant)
Access and sharing policies and processes	- Standardised (3) *	-

Table 3c: Biobank Access and Standards

	Unanimous decision (# of participant)	Split decision (# of participant)
Biobank continuation	Standardized (3)*	-
Biobank Intellectual Property (IP)	Harmonised (3)*	-
Biobank Incidental Findings (IF) and Return of Individual Research Results (IRR)	Harmonised (3)*	-

Table 3d: Continuation, Intellectual Property, IF and Return of IRR

Conclusions

Other types of biobanks exist, structures and features can by used, primary care remains an intermediary between medicine and public health, thus the population and type of research are highly specific

Identified key components of a primary care based biobank and incorporated stakeholder perspectives

Too often interventions are developed without input of the people who are expected to deliver on the intervention in their workflow and workspace. Highly recommended to use sociotechnical processes to integrate technology in an organisation or healthcare system.