Health Data Cooperatives

Are Health Data Cooperatives the Way Forward for Minority Communities?: A Scoping Review
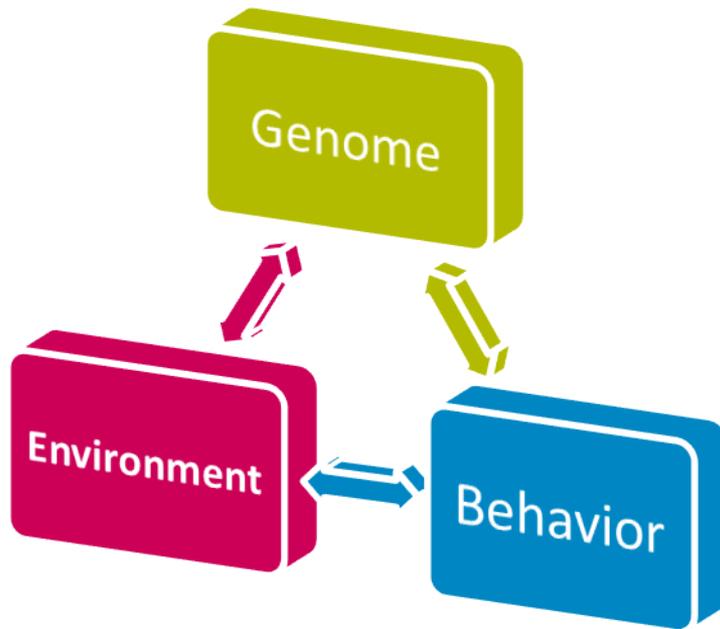
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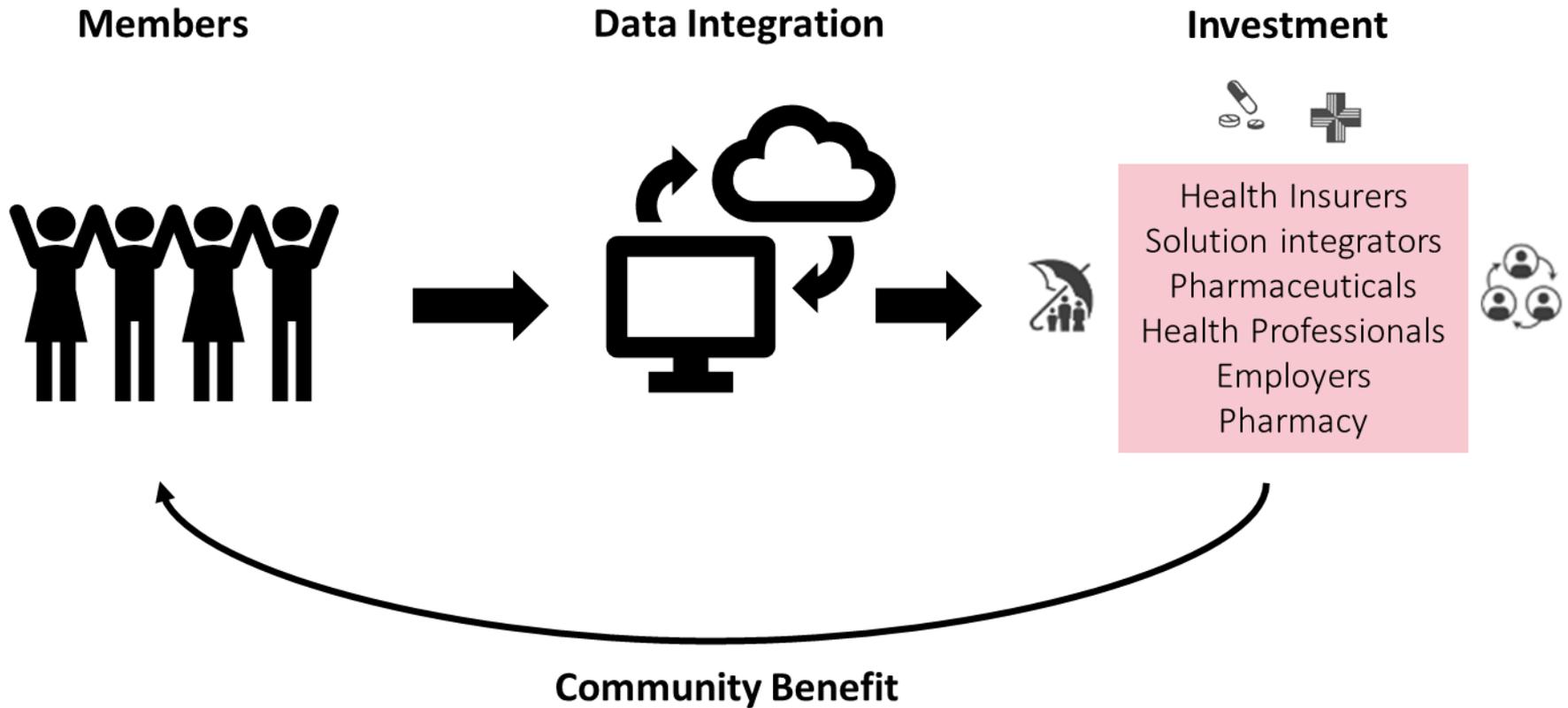
The Importance of Health Data

- Public Health improvement requires the study interaction between the genome, environment, and behavior

- Data is become increasingly more available and valuable for each aspect of this triage

- Health data is available from multiple modalities:
  E.g. Personal health apps, Physician offices, Laboratories

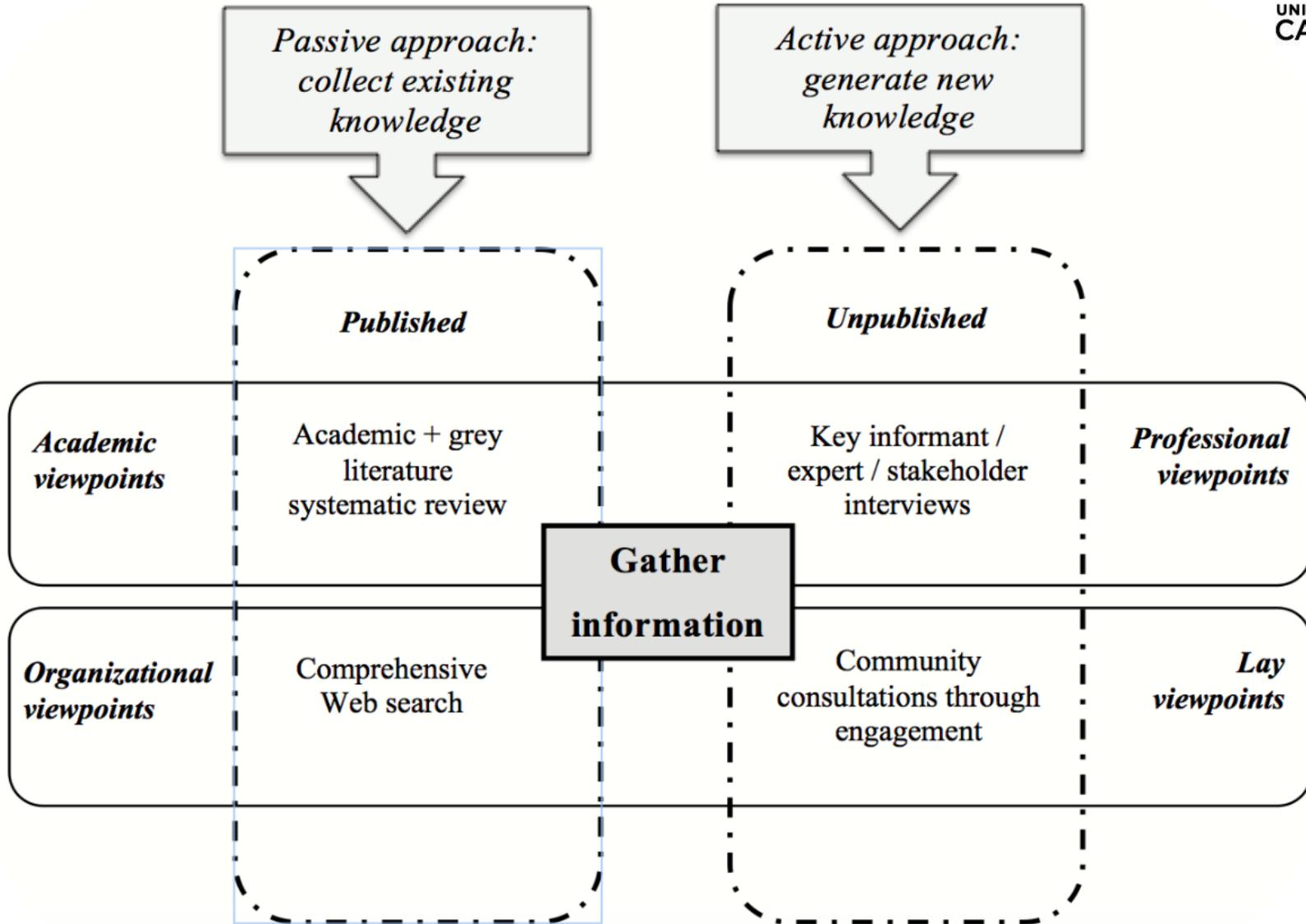What problems could arise when integrating data across multiple platforms?

Health Data Cooperatives (HDC)

Members

Data Integration

Investment

Health Insurers
Solution integrators
Pharmaceuticals
Health Professionals
Employers
Pharmacy

Community Benefit

Methodology: The Scoping Review

1	2	3	4	5
Identifying Research Question	Identify relevant studies	Study Selection	Charting Data	Summarizing Results

Arksey and O'Malley, 1997

1

Identifying Research Question → Identify relevant studies → Study Selection → Charting Data → Summarizing Results

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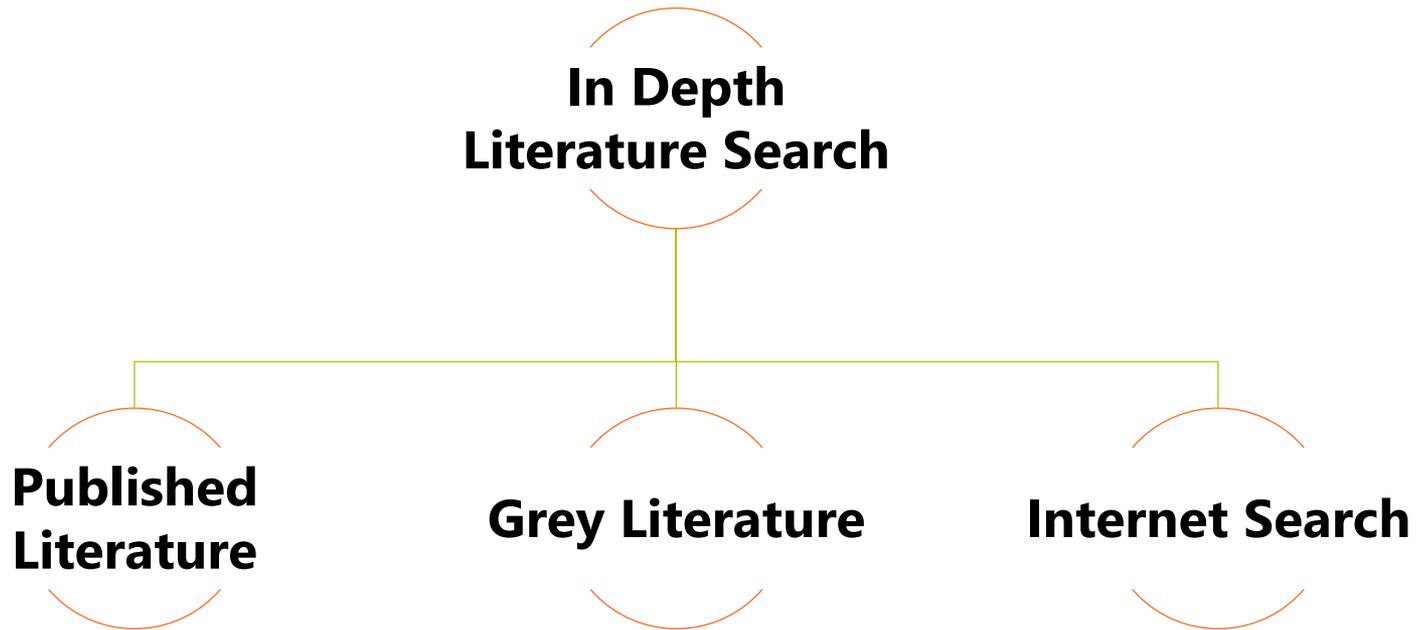
Two non-limiting questions will be explored:

1. What are the aspects of HDCs that matter to different stakeholders

2. What are the benefits and Challenges related to the HDC model

In Depth Literature Search

Published Literature

Grey Literature

Internet Search

3

Identifying Research Question → Identify relevant studies → Study Selection → Charting Data → Summarizing Results

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In Depth Literature Search

Published Literature — Grey Literature — Internet Search

Two levels of screening to determine records that reported on any aspect of HDCs

First 10 pages of search were archived and screened for relevance. A second reviewer arbitrated

Identifying Research Question → Identify relevant studies → Study Selection → Charting Data → **Summarizing Results**
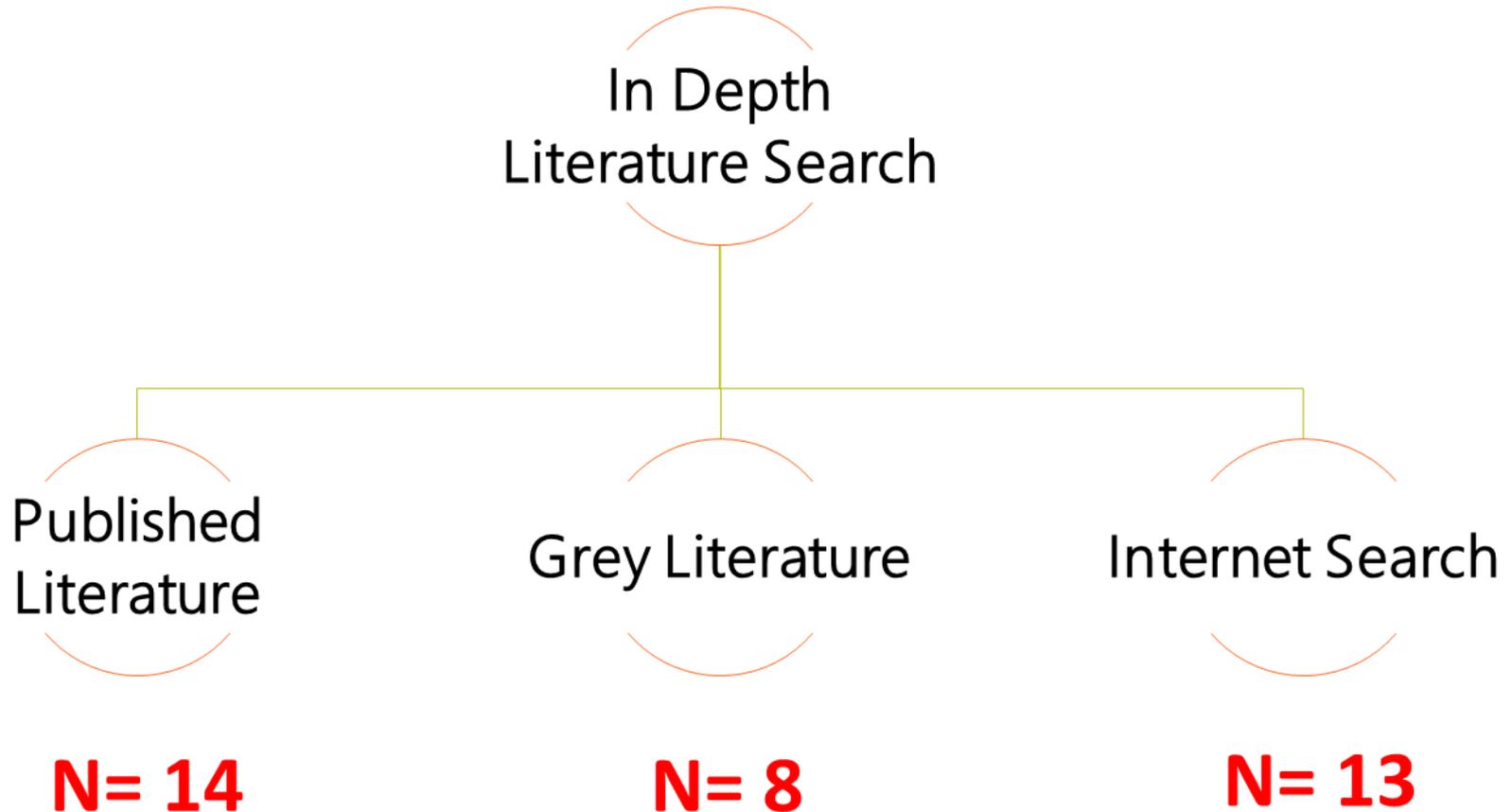
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1. Thematic analysis of results → themes were adjusted iteratively
   - Benefits and challenges related HDC models were then stratified by these themes.

2. World cloud analysis – visual representation of word frequency

Results: Included Studies

In Depth
Literature Search

Published
Literature

Grey Literature

Internet Search

N= 14

N= 8

N= 13

Results: Database and Grey Literature

Publication date
- No Studies Published before 2000
- Increase in studies after 2015

Study Location
- All studies are from developed nations
- Most studies form US

Author Affiliation
- Largely Academic

Target Audience
- Policy and Academia

Results: Internet Search

Publication date
- Unable to determine

Study Location
- Site largely from US and Europe

Author Affiliation
- Affiliation were private companies

Target Audience
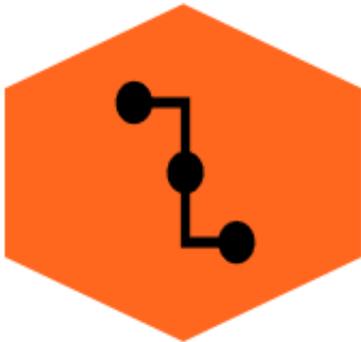- Largely for lay audience and academics

Results: World Cloud Analysis

Database and Grey literature

Internet Search

Results: Thematic Analysis

Results: Data Flow and Infrastructure

Benefits	Challenges

- Data integration: use of data from multiple modalities

- Data Dissemination: investment of data to interested stakeholders

- Sociopolitical system of the host context must be considered.

- Homogenous cooperative may be more successful

- Too much data may be a problem!

Results: Data Ownership

Benefits	Challenges
• Can operate with minimal costs without charging participants • Democratic structure allowing for data access, data use, and governance • Empowerment and control to pitch to invest to stakeholders	• Political and bureaucratic hurdles • Loss of autonomy due to connections with structural stakeholders and government • Overrepresentation of certain people views can lead to distrust

Results: Data Security
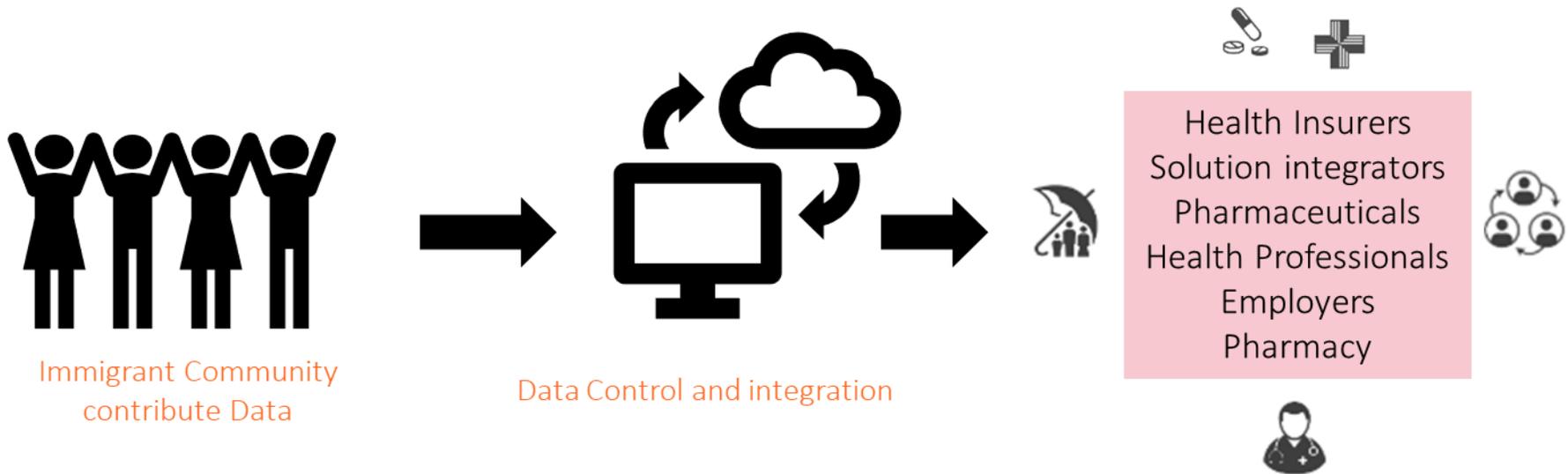
Benefits	Challenges

- Securely store data from multiple platforms

- Regulatory bodies and governance structures that improve data security and transparency.

- Large data repositories are a threat to cyber attacks.

- Fear of the lack of transparency and security.

Applications: Immigrant Health

- Canada welcomes 250 000 immigrants each year, contributing to 20% of the population

- In the case of Immigrant Health – data is a limiting factor

- Comprehensive national knowledge on immigrant health and health service utilization is limited – meaningful comparisons cannot be made!

- Key knowledge gaps in immigrant health include: long-term health outcomes, preventable conditions, and chronic disease outcomes, especially amongst subgroups such as refugee and non-European immigrants

Applications: Immigrant Health

Immigrant Community contribute Data

Data Control and integration

Health Insurers
Solution integrators
Pharmaceuticals
Health Professionals
Employers
Pharmacy

Immigrant groups can contribute to a HDC model:

- Empower individuals to manage their health and build resiliency
- Help contribute to the care of their community
- Invest is targeted health intervention

Discussion and Questions

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Educational interests lie in social determinants of health and health equity and focus on ethnic differences in cardiovascular disease risk factors in Canada.

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 IRH Interest Group @IRInterestGroup

Research interests are challenges in access to care and unmet needs faced by the socially vulnerable population of the society, including new immigrants, refugees, and ethnic communities. He leads his program of research through the approach of Community Based Participatory Research and Integrated Knowledge Translation where efforts for Meaningful Community Engagement is at the core

Disclosure Statement

- I have no affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization.