

# Empowering immigrant community through ownership, control, possession and utilization of data: Community Based Health Data Cooperative



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## Background

- Canadian immigrant populations come from diverse ethno-geographical backgrounds and exhibit differences in their culture and understanding of health and wellness.
- Immigrants make more than 20% (eight million) of the total Canadian population, representing two-thirds of nation's population growth. It is imperative to collaborate and empower these diverse communities.
- This can be achieved through establishing a health data cooperative (HDC) that allows the availability of the valuable data for societal purposes.
- HDC is a health data bank where cooperative members collect, store, use and share health-related data (e.g., health condition, lab results, social determinants of health data, etc.).

## Objectives

- The aim of this review is to analyze the feasibility of immigrant based HDC model through conducting stakeholder and customer discovery interviews to gain insights and conduct early-stage assessments determining sustainability and scalability of the HDC.



Figure 1: How Health Data Bank will Operate?

## Methods

- We propose to undertake a comprehensive environmental including stakeholder analysis to conduct key-informant interviews.
- Through the interviews, we will gather feedback and research existing models of cooperatives to develop the HDC framework.
- Build a diverse interdisciplinary team comprised of immigrant-community members, academics, policymakers, and non-governmental organizations on the initiative of HDC

## Results

- Through this comprehensive environmental scan, we are hoping to engage stakeholders and explore key components such as ethical & legal frameworks, organization management, data security, privacy, computing science, knowledge mobilization, and community development.
- We believe by enabling the immigrant communities has the potential to promote health equity through empowerment (enhance individual competence & self-esteem, increase community action & participatory learning exercises).

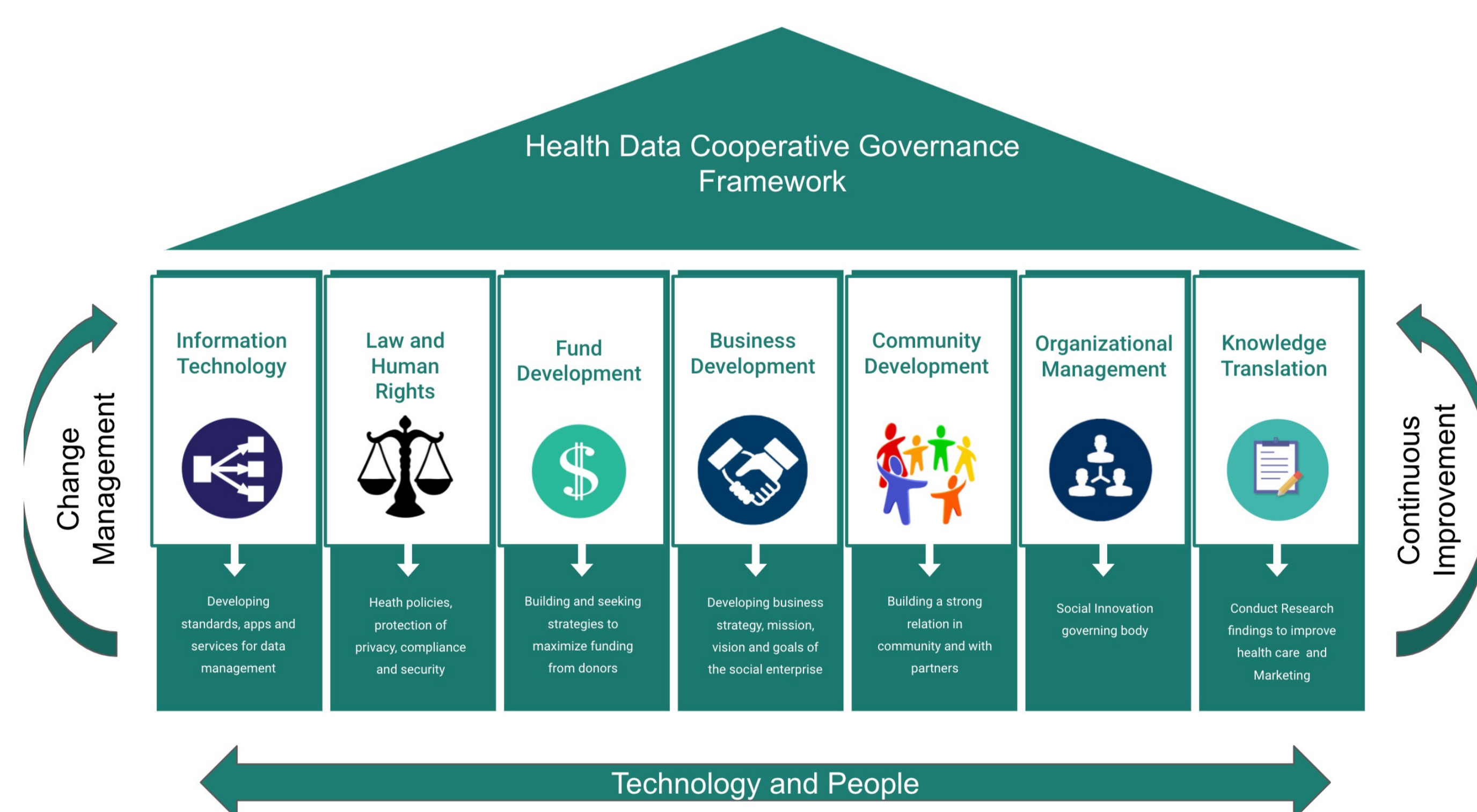


Figure 2: Health Data Governance Framework

## Conclusions

- The results of this project are an informative first step to launch a pilot HDC model in immigrant communities.
- Moreover, further research on scalability and performance would be required as the HDC model becomes operational.

## References

Turin, T C et al. "Community-based Health Data Cooperatives Towards Improving the Immigrant Community Health: A Scoping Review to Inform Policy and Practice." International journal of population data science vol. 5,1 1158. 23 Jun. 2020, doi:10.23889/ijpds.v5i1.1158