



GenomeCanada

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Enhancing Canada's Population Cohort Environment:

Recommendations of the Pan-Canadian Population Cohorts Working Group

Prepared for the Genome Canada Science and Industry
Advisory Committee and Canadian Institutes of Health
Research Science Council

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1. Executive Summary

The health of a nation, as well as its wealth and ability to innovate, are increasingly dependent on the availability of detailed population health data. A critical source of this population health data are population cohorts—a defined population selected for longitudinal assessment to gain insight into factors that influence health. Many countries around the world are making significant investments in national health databanks and large-scale cohorts, taking portfolio approaches to cohort studies, linking large and more niche resources and filling gaps with new, large-scale efforts.

In Canada, there are currently >50, high-quality population-based cohorts. These studies vary in terms of size, representativeness and data collected, and they are operating in parallel to growing investment establishing Canada as a leader in artificial intelligence, machine learning, and data standards/frameworks for data sharing. The value of these efforts has accrued over time as datasets have gotten richer, supporting hundreds of teams to ask questions of relevance to the health and wellness of Canadians, producing science and publications that address national concerns (e.g. correlates to adherence to cancer screening uptake, risks to environmental exposures, factors for healthy aging, gene-environment interactions, racial inequities of COVID-19) and establishing foundational background genetic studies that will inform future scientific endeavors.

Despite the quality of these efforts, key system gaps hinder the extraction of the full value of population cohorts, including barriers to administrative data access, lack of representation reflective of Canada’s diverse population, lack of Indigenous-led cohorts, data sharing and harmonization challenges, lack of sustainable funding and low public awareness. COVID-19 has further exposed the gaps that we must close, demonstrated the agility of studies in engaging their participants, raised some awareness on the value of population cohorts among the public and improved the public sentiment around data sharing and use for research.

Overall, if Canada is to translate cohort research outputs into more meaningful impact and benefit for people, a more holistic approach that brings together diverse viewpoints is needed to identify opportunities to enhance the landscape and position collective efforts at the forefront of population health research.

Recognizing the different conversations about these issues in pockets of the research community, Genome Canada and CIHR initiated work to bring these conversations into a collective discussion. An expert Working Group (WG) with diverse experience and expertise was therefore formed to lead a strategic engagement process.

The mandate of the WG was to guide the development of a consultative process related to the cohort landscape in Canada and, from that consultation, provide specific recommendations to CIHR and Genome Canada to inform the following questions:

- **Do we need to evolve the population cohort landscape in Canada?**
- **To what extent can we leverage existing cohorts and infrastructure?**
- **How can we advance this work?**

A broad information-gathering effort was launched from March 2020 to June 2021¹ and included expert deliberation based on the experience of the WG members, panel discussions (focused on international cohort practices and lessons learned, data considerations and principles and Canadian cohort studies), and a two-day workshop with representation from diverse fields of study. Based on the input from a variety of groups, the WG deliberated and collaboratively formulated key recommendations for Canada's population cohort environment.

Based on consensus from the WG, answers to the guiding questions were resolved:

Do we need to evolve the population cohort landscape in Canada?

- **The answer to this is an unequivocal yes.** There are many strengths in the existing cohorts in Canada, but it is also clear that the current landscape could be better organized in line with broader ambitions.
- **A new, large pan-Canadian cohort would be challenging given the need for Indigenous populations to independently lead efforts and maintain appropriate degrees of data autonomy along with difficulties integrating data across provincial healthcare systems.**
- **Despite this, there are indeed opportunities to evolve the population cohort landscape** i) to be more enabling of new health care and wellness paradigms and a skilled workforce, ii) to be more diverse, and iii) to help realize the cohort ambitions of First Nations, Inuit and Métis populations.

To what extent can we leverage existing cohorts and infrastructure?

- **Leveraging what we have now is key, so that we benefit from investments that have been made in existing cohorts.**
- To do so, we must first focus on, through further significant funding, enhancing and harmonizing existing cohorts, setting common data standards and establishing trusted research environments that link data; remaining gaps could be closed *in the future* with any additional cohort(s), if necessary.

¹ During the summer and fall of 2020, the process was largely paused due to COVID-19.

How can we advance this work?

- **Collective input and action will be important for moving forward on this discussion and recommended activities.**
- A coordinating body should be established to highlight major gaps, set a vision and broad strategic objectives that existing cohorts cannot necessarily address that help to guide implementation of recommendations. This will require deeper knowledge of existing assets to define granular action plans.
- The public also needs to be further engaged and involved to understand their expectations and policymakers need to further understand the benefit of cohorts to secure needed long-term and sufficient financial commitment.

Given this, 11 specific recommendations emerged, considering the evidence gathered and experience of the WG. These recommendations are not necessarily presented in the order in which they should be implemented but rather by the WG’s guiding questions/theme. It is recognized that implementation of the recommendations will be complex and for this reason, WG members, with our expertise and experience, can be made available to act as a sounding board to Genome Canada and CIHR as they consider next steps.

Theme	Recommendation
Evolving the population cohort landscape in Canada	<p>#1: Increase the diversity of participants across Canada’s cohort landscape to deliver more equitable outputs that are beneficial to all.</p> <p>#2: Facilitate self-determination efforts of First Nations, Inuit and Métis populations to realize each of their cohort ambitions in alignment with established data strategies and principles², and partnership expectations.</p> <p>#3: Enhance Canada’s cohort landscape with an intention to enable new research, healthcare, wellness and economic paradigms.</p>
Leveraging existing cohorts and infrastructure	<p>#4: Enhance and harmonize <i>existing</i> cohorts while evaluating the need for any additional cohort(s) to fill remaining gaps across the portfolio.</p> <p>#5: Set, and support and incentivize adherence to, common data standards according to FAIR³, CARE⁴ and TRUST⁵ principles that foster interoperability and data sharing within a federated data model and operate under ethical governance frameworks.</p> <p>#6: Establish or expand upon trusted research platforms that bring together data, integrate analytical tools and capabilities and draw information from administrative systems.</p>
Advancing this work	<p>#7: Establish a Coordinating Body with diverse membership, suitable governance structures and appropriate authority, respecting First</p>

² E.g. First Nations Principles of OCAP® (Ownership, Control, Access, and Possession), Métis Provincial organizations’ data principles and Inuit Tapiriit Kanatami National Strategy on Inuit Research

³ FAIR = Findable, Accessible, Interoperable, Reusable

⁴ CARE = Collective Benefit, Authority to Control, Responsibility, Ethics

⁵ TRUST = Transparency, Responsibility, User focus, Sustainability and Technology

<p>Nations, Inuit and Métis relationships with Federal/Provincial/Territorial governments, in order to set a unifying vision, prioritize strategic objectives and translate the WG’s recommendations into tailored action plans.</p> <p>#8: Conduct a more detailed landscape assessment to fully understand existing assets and gaps in the cohort landscape to inform specific action plans and deliver on recommendations.</p> <p>#9: Engage with and involve the public, potentially in collaboration with other data-related initiatives (e.g. pan-Canadian Health Data Strategy, Indigenous data strategies), to understand expectations, build momentum and foster trust.</p> <p>#10: Formulate strategies and approaches, and work with complementary initiatives to address systemic, jurisdictional barriers around data sharing, administrative data linkages, privacy and risk.</p> <p>#11: Secure sufficient, long-term financial commitments by communicating the value and impact of an enhanced cohort landscape in alignment with policymakers’ priorities.</p>
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With the public’s heightened awareness of the importance of health data due to the COVID-19 pandemic, unprecedented levels of data being generated, and the increasing power of analytical and data sharing tools, there has never been a more salient moment to create a population cohort environment that acts as a national resource linked to promoting the health of people living in Canada. **By setting a compelling vision, advancing recommendations and demonstrating near-term positive impact, the WG believes Canada will be better positioned to capitalize on cohort outputs and improve the health and wellness of Canadians while also benefiting from an elevated status as a go-to international partner for research.**



2. Introduction

The health of a nation, as well as its wealth and ability to innovate, are increasingly dependent on the availability of detailed population health data. By leveraging large-scale national health datasets, it is possible to interrogate genetic, environmental, economic and social factors; understand how they interrelate; identify disease risk factors; inform the development of health innovations; guide more personalized healthcare; and advance population-level solutions that improve health outcomes and reduce overall healthcare costs. **Population cohorts—a defined population selected for longitudinal assessment to gain insight into factors that influence health—are a critical source of population health data.**⁶

International investment in population cohorts

Many countries around the world are making significant investments in national health databanks and large-scale cohorts. Key initiatives include: USA's [All of Us](#) precision medicine initiative; UK's [CLOSER](#) and the [UK BioBank](#); Japan's [Tohoku Biobank](#); China's [Kadoorie Biobank](#); Sweden's [LifeGene](#), France's [Constances population-based epidemiological cohort](#), among others. Moreover, global initiatives, such as the [International 100K Cohort Consortium \(IHCC\)](#), have launched with a focus on bringing these large-scale initiatives together, encouraging data sharing, improving efficiencies and addressing scientific questions none could answer alone.

Recently, leading jurisdictions like the UK are increasingly taking a *portfolio approach* to population health data/cohorts, making connections between large NHS resources and more niche studies and establishing single sign-in portals, while filling gaps along the way. Similarly, the US is also making *diverse investments*, assembling a network of cohorts (e.g. IHCC) to leverage and amplify existing assets while creating new cohorts (e.g. All of Us) that address specific opportunities.

Canada's population cohort environment

In Canada, there are currently [over fifty population-based cohorts](#). Examples include: [Canadian Partnership for Tomorrow's Health \(CanPath\)](#); [Canadian Longitudinal Study on Aging \(CLSA\)](#); [CHILD Cohort Study](#); [Maternal-Infant Research on Environmental Chemicals \(MIREC\)](#); and the [Aboriginal Birth Cohort](#). Cohorts in Canada vary in terms of size, representativeness and data collected but generally, there are several high-quality studies with strong scientific potential and of high interest to Canadian and international researchers.

⁶ Definition modified from [Szklo, 1998. Population-based Cohort Studies](#).

In parallel, Canada is also emerging as a global leader in artificial intelligence (AI), machine learning (ML), and frameworks and standards for data sharing, with national strategies and international connections in data science that can be accelerated further through cohort efforts (and vice versa).

The value of these efforts has accrued over time as datasets get richer, supporting hundreds of research teams' efforts to answer questions of relevance to the health and wellness of Canadians. These efforts are producing data and publications that address national concerns (e.g. correlates to adherence to cancer screening uptake, risks to environmental exposures, factors for healthy aging, gene-environment interactions, racial inequities of COVID-19) and establishing foundational background genetic studies that will inform future scientific efforts.

However, key gaps and barriers exist, including (but not limited to):

- **Lack of Representation:** There remains inadequate diversity within or among many cohort efforts, leaving behind groups typically underrepresented in health research.
- **Lack of Indigenous-led Cohorts:** Despite feasibility studies, First Nations, Métis and Inuit populations lack the financing and recognition of self-determination by data holders that are necessary to create and advance efforts aligned with established data ownership/governance principles and strategies, and expectations of autonomy.
- **Administrative Data Access Barriers:** Despite that in many cases cohort participants have given express consent for data linkage, with healthcare operating under provincial jurisdiction, regional laws and the highly risk-averse interpretation of privacy legislation complicates inter-provincial data access. This sharing of data may become less of a barrier under appropriate governance structures (e.g. federated data infrastructure).
- **Data Harmonization and Sharing Challenges:** With varying data access environments, standards, and diverse consent parameters limiting access, there is a high degree of heterogeneity associated with data that can prevent harmonization and sharing.
- **Lack of Sustainable Funding:** As a country, Canada has not prioritized cohort studies as national resources and lacks a dedicated funding envelope for related efforts.
- **Low Public Awareness:** A lack of high visibility communication and stories on the value of cohort research and collaboration has hindered the public's knowledge and downstream advocacy for such cohort studies.

COVID-19's influence on the cohort environment

COVID-19 has had (and continues to have) an enormous impact on the world and the lives of all Canadians—and the research enterprise was not immune to its devastating toll. The pandemic has slowed non-COVID-19 related research, created challenges in participant recruitment and retention and impacted funding and staffing. Yet, despite the impact and the tragedies that cannot be diminished, COVID-19 has in many ways exposed the gaps in population health research that we must close, demonstrated the agility of studies in engaging their participants, raised awareness on the value of population cohorts among the public and improved the public sentiment around data sharing and use for research.

Overall, if Canada is to extract maximum value from cohort studies, translating research outputs into meaningful impact and benefit for people living in Canada and positioning Canada as a go-to research partner on the international scene, a more holistic approach that brings together diverse viewpoints and identifies opportunities that serve everyone is needed.

3. Working Group Mandate and Process

There are different pockets of activity underway across Canada focused on addressing data needs. To bring these activities together into one common discussion, Genome Canada and CIHR sought to advance collective thinking on the opportunities that exist to optimize collection and analysis of social, economic, environmental, health care, lifestyle, and human biological data in a manner that reflects Canada's unique population, including Indigenous populations and groups typically underrepresented in health research.

A Working Group was established to advise on the strategic importance and opportunity to enhance and evolve the Canadian cohort landscape. The mandate of the Working Group was to guide the development of a consultative process related to the cohort landscape in Canada and, from that series of engagements, provide specific recommendations to CIHR and Genome Canada to inform the following questions:

- **Do we need to evolve the population cohort landscape in Canada?**
- **To what extent can we leverage existing cohorts and infrastructure?**
- **How can we advance this work?**

The Working Group (WG) consisted of 22 members, some of whom are leading experts from relevant fields and others who bring an informed public perspective. The WG was chaired by **Dr. Fiona Brinkman**, Distinguished Professor, Department of Molecular Biology and Biochemistry and Associate Member, School of Computing Science and Faculty of Health Sciences, Simon Fraser University and **Dr. Marc Gunter**, Section Head, Nutrition and Metabolism, International Agency for Research on Cancer, World Health Organization. The WG oversaw a multistep process (blue boxes) that comprised multiple activities (see figure bullets; only key activities shown).



*The process was paused for much of 2020 as a result of COVID-19

4. Recommendations

Overview

Stemming from a broad information-gathering effort and input from a variety of groups, the WG deliberated and collaboratively formulated key recommendations for Canada's population cohort environment. These recommendations were driven by the guiding questions that the group was mandated to address. When assessing the ideal path forward, the WG factored in our existing knowledge of the Canadian cohort landscape (albeit limited, see Recommendation #8), the structure of the Canadian political and healthcare system and the related realities in terms of Federal, Provincial and Territorial data ownership and jurisdiction, international best practices, and efforts to harmonize cohort data along with data standards that can permit ongoing and future national and international collaboration.

Based on consensus from the WG, it was concluded that:

- A *new*, large pan-Canadian cohort would be challenging given the difficulties integrating data across healthcare systems and the need for Indigenous populations to independently lead efforts and maintain data autonomy.
- Despite this, there were indeed opportunities to evolve the population cohort landscape i) to be more enabling of new health care and wellness paradigms and a skilled workforce, ii) to be more diverse, and iii) to help realize the cohort ambitions of First Nations, Inuit and Métis populations.
- To do so, existing cohort investments should be leveraged to the greatest degree possible, focusing first on, through significant funding, enhancing and harmonizing existing cohorts, setting common data standards and establishing trusted research environments that allow for data linkages; remaining gaps could be addressed *in the future* with additional cohort(s), if necessary.
- To help advance this work, a coordinating body should be established to highlight major gaps, set a vision and broad strategic objectives that existing cohorts cannot necessarily address to help guide implementation of recommendations. This will require deeper knowledge of existing assets to define granular action plans.
- The public also needs to be actively engaged and involved to understand their expectations and policymakers need to better understand the benefits of cohorts to secure sufficient, long-term financial commitment.

Given this, 11 specific recommendations emerged, considering the inputs gathered and experience of the WG. **These recommendations are not necessarily presented in the order in which they should be implemented but rather, are organized by the guiding questions.** Estimated costs associated with particular activities are provided in detailed descriptions, *where possible*, though a more thorough cost-benefit analysis is warranted by groups who will oversee the work going forward.

GUIDING QUESTION #1: DO WE NEED TO EVOLVE OUR POPULATION COHORT LANDSCAPE IN CANADA?

Recommendation #1: Increase the diversity of participants across Canada's cohort landscape to deliver more equitable outputs that are beneficial to all.

The opportunity to enhance diversity across the cohort landscape was deemed of high importance to address (in addition to public engagement; **see Recommendation #9**). Through expert consultation and workshop discussions, there was nearly universal agreement that there are several underrepresented groups, including Indigenous populations (**see Recommendation #2**), newcomers to Canada, racialized minorities, individuals living in rural regions, among several others. Indeed, national efforts in other countries such as the All of Us cohort study, recognize the importance of diversity to maximize value and given Canada's unique and wide diversity, we can make this a strength of our cohort landscape and a selling point for partnerships globally. Future discussions should determine the value of niche cohorts dedicated to specific populations and harmonized with the larger landscape and/or expansion of existing studies with concerted focus on diversity.

Through diversity, Canada can ensure that its cohort studies represent all persons living in Canada and provide outputs that enable disaggregated data analysis and better evidence-based decision-making.

Recommendation #2: Facilitate self-determination efforts of First Nations, Inuit and Métis populations to realize each of their cohort ambitions in alignment with established data strategies and principles⁷, and partnership expectations.

Despite historical efforts (e.g. First Nations Regional Health Survey) and feasibility studies identifying opportunities for First Nations, Inuit and Métis populations, each remains highly underserved and underfunded regarding the development of culturally appropriate, *independently-led* cohort studies.

⁷ E.g. First Nations Principles of OCAP® (Ownership, Control, Access, and Possession), Métis Provincial organizations' data principles and Inuit Tapiriit Kanatami National Strategy on Inuit Research

Recognizing that “one size doesn’t fit all”, a distinctions-based approach will be critical to the successful development of Indigenous population cohort efforts, acknowledging and working through distinct (i) partnership beliefs (e.g. Nation-to-Nation), (ii) governance strategies (e.g. regional, sub-regional), (iii) data ownership expectations (e.g. OCAP principles for First Nations and equivalents), (iv) considerations that address participants’ concerns and historical distrust and stigmas, and (v) culturally-safe, well-resourced and robust engagement methods (e.g. moving from broad conversations to more regional, focused conversations by working with, for example, Inuit Tapiriit Kanatami (ITK) and gathering local advice) that lead to trustworthy relationships.

Approaches to funding Indigenous cohort efforts will need careful consideration as historically, Indigenous and Northern Affairs Canada (now known as Crown-Indigenous Relations and Northern Affairs Canada (CIRNAC)/Indigenous Services Canada (ISC)) has directed that related financial support and future plans should consider advantages and limitations to this model.

A practicable approach that delivers financing and recognition of self-determination by data holders for Indigenous populations can provide traction for long-standing ambitions around cohort studies that address needs and promote health while adhering to expected principles from inception.

Recommendation #3: Enhance Canada’s cohort landscape with an intention to enable new research, healthcare, wellness and economic paradigms.

Based on preliminary surveys of both public and expert academic perspectives, workshop discussions and the WG input, there is *overwhelming agreement* that Canada needs to enhance its population cohort efforts to fill existing population health data gaps. The evolution of the cohort landscape should be in alignment with a larger population health vision and in service of scientific objectives that cannot be addressed with existing assets (e.g. Healthy Kids to better profile what makes children healthy, engaged populations including Indigenous populations and more diverse populations; **see Recommendation #7 on setting a more specific vision and objectives**). The evolution of cohorts must position the landscape to enhance our research capabilities and deliver more equitable research outputs (**see Recommendation #1 & 2**) but also to accelerate the development of innovations, enable new prevention and care strategies (e.g. precision medicine, precision prevention solutions), and leverage and accelerate our capabilities and workforce in AI and machine learning, which are all becoming mainstays for 21st-century healthcare and wellness.

"Canada is in the 'Stone Age' compared with countries like US and UK. Every population health hypothesis that I think of is better tested with data from elsewhere (even when the health question is a priority to Canadians)."

-- Expert survey respondent

"Without concerted effort to improve our population specific health knowledge, we will continue to use our existing blunt instruments to address health issues that require precision...and the same populations will continue to be negatively impacted."

-- Non-expert survey respondent

With an ambition that links more closely to the health of people living in Canada and economic benefits, the population cohort environment can further cement itself as a vital, long-term resource recognized by policymakers and the public.

Guiding Question 2: To what extent can we leverage existing cohorts and infrastructure?

Recommendation #4: Enhance and harmonize existing cohorts while evaluating the need for any additional cohort(s) to fill remaining gaps across the portfolio.

With several high-quality large-scale and small-scale studies underway in Canada, a wealth of resources (e.g. infrastructure, data, analytical tools), connections with participants and rare expertise (e.g. among cohort leaders and the community that uses the data) has amassed over the years. However, we have yet to realize the full collective value of these population cohort studies given the limitations identified previously. In lieu of *immediately* establishing a new cohort, the Working Group recommends that Canada first enhance the cohort assets by expanding (e.g. underrepresented populations) and integrating (e.g. data sharing/linking) existing cohort studies. Importantly, any efforts to expand and enhance existing cohorts must be careful not to exacerbate any inequities that may exist.

Subsequently, there may still be a need for (an)other cohort(s), to close gaps across the life course or to address other opportunities of relevance to Canadians that bring us closer to an optimal state and a more comprehensive portfolio of studies (**see vision development in Recommendation #7**) addressing Canada's needs. Based on the experience of the WG, we believe a meaningful commitment will be required to advance this work, building on the already significant investment to date (though more exhaustive cost analyses are needed).

With an integrated cohort landscape, Canada can take more of a portfolio-based approach, achieving the level of granularity necessary to answer specific research questions within a single, targeted cohort and the ability to answer broader questions through a harmonized and coordinated landscape.

Recommendation #5: Set, support and incentivize adherence to, common data standards according to FAIR, CARE and TRUST principles that foster interoperability and data sharing within a federated data model and operate under ethical governance frameworks.

As Canada continues to advance a variety of cohort studies, there is an opportunity to set common standards and principles that allow for greater crosstalk, collaboration, data sharing, insight generation and long-term value creation under a model that recognizes existing jurisdictional structures and data ownership. Specifically, the WG believes that a federated data model (see box for a brief definition) is most appropriate for the jurisdictional realities around data ownership. Approaches to align cohorts on data standards will be required, building on Global Alliance for Genomics and Health (GA4GH) standards, adhering to **FAIR**⁸, **CARE**⁹ and **TRUST**¹⁰ principles and promoting common collection, storage, security, curation, access and use of data for all studies (e.g. common validated survey instruments around race, ethnicity, gender, etc.). Methods to incentivize and enforce standards, (e.g. making funding contingent on the adherence of these standards) should be considered, while ensuring that any approaches do not create or increase inequities. Furthermore, support to meet these standards (e.g. workshops, training tools, etc.) should be provided, potentially in collaboration with groups already offering these services.

A federated model for data sharing requires organizations to host data independently and to interoperate via an agreed-upon technical language. This model removes the inefficiencies of large data transfers and gives host organizations more control over data privacy, security and representation.

By setting principles and governance structures built around achieving a common goal for population cohorts and population health, Canada can more readily harmonize efforts, promote data sharing and importantly ask and answer more complex questions related to the health of people living in Canada.

Recommendation #6: Establish or expand upon trusted research platforms that bring together data, integrate analytical tools and capabilities and draw information from administrative systems.

As the paradigm shifts from 'data copying' to 'data visiting', access to information increasingly comes with the analytical tools, capabilities to mine the information as well as the potential to create virtual cohorts in data environments. The WG recommends building on (e.g. Calcul Quebec, SecureData4Health) and/or creating complementary trusted research environments (e.g. virtual data labs) that draw on a variety of data sources (inclusive of administrative data and across cohorts) and respect national and regional

⁸ FAIR = Findable, Accessible, Interoperable, Reusable

⁹ CARE = Collective Benefit, Authority to Control, Responsibility, Ethics

¹⁰ TRUST = Transparency, Responsibility, User focus, Sustainability and Technology

processes and consent parameters. It is recommended that open software models be applied and customized to be fit-for-purpose and enabled by interoperability principles/standards (**see Recommendation #5**). GA4GH standards around data use and researcher identities can provide a platform on which to build.

Trusted research environments can create secure platforms for researchers across the cohort community, operating under a federated model and connecting nodes across the country for a one-stop data shop.

Guiding Question 3: How do we advance this work?

Recommendation #7: Establish a Coordinating Body with diverse membership, suitable governance structures and appropriate authority, respecting First Nations, Inuit and Métis relationships with Federal/Provincial/Territorial governments, in order to set a unifying vision, prioritize strategic objectives and translate the WG's recommendations into tailored action plans.

One of the initial challenges that catalyzed the formation of the WG was the disparate conversations and initiatives occurring across the country in a somewhat uncoordinated manner. For this reason, the WG is recommending the formation of a Coordinating Body that can bring together planning efforts related to population cohorts and integrate an overarching strategic lens on the landscape while respecting First Nations, Inuit and Métis relationships with Federal/Provincial/Territorial governments. It will be critical to undergo a planning effort to establish this body, determine its strategic priorities, set a governance structure that provides it with appropriate authority (e.g. to set standards, ensure agreement and adherence by funders) and determine its optimal membership. Indeed, while this Coordinating Body should be likely comprised of experts in the field, the selection of the body's membership should *not* exacerbate inequities but strive for inclusive excellence (i.e. have representation from different groups including the public, underrepresented groups as well as clinicians, system administrators and experts from parallel and complementary strategies (e.g. the pan-Canadian Health Data Strategy). The Coordinating Body would ideally begin by setting a unifying vision for the cohort landscape, informed by a more detailed landscape assessment (**see recommendation #8**) in order to customize action plans that can deliver on the recommendations and move Canada closer to the vision itself.

With a dedicated Coordinating Body provided with sufficient resources, Canada can better coordinate efforts, achieve consensus on a vision and scientific objectives for the future and create a group accountable for overseeing and delivering on the recommendations.

Recommendation #8: Conduct a more detailed landscape assessment to fully understand existing assets and gaps in the cohort landscape to inform specific action plans and deliver on recommendations.

A common information gap identified consistently throughout the WG’s process is a detailed understanding of the existing cohort landscape in Canada. In support of a more strategic approach to future actions, the WG recommends a more in-depth and thorough assessment of the population cohort landscape in Canada, potentially building on the foundation established by [Maelstrom](#). This assessment should focus on areas including (but not limited to): what data are collected and from whom, profiles of participants in existing studies (and who is underrepresented), consent parameters and any associated limitations to share/link data. For such a study, proper scoping in consultation with experts is recommended in addition to a significant financial commitment needed to deliver a highly rigorous review across the national landscape.

The knowledge gained from a robust landscape assessment will allow the Coordinating Body (and partners and funders) to have a greater level of confidence in the gaps that need to be addressed, ultimately making more optimal use of resources going forward.

Recommendation #9: Engage with and involve the public, potentially in collaboration with other data-related initiatives (e.g. pan-Canadian Health Data Strategy, Indigenous data strategies), to understand expectations, build momentum and foster trust.

Despite the thousands of individuals that participate in population health research, the public remains somewhat unfamiliar with cohort studies, indicating further engagement, education and knowledge mobilization efforts are needed. The responsibility of raising awareness likely requires collaboration and the WG recommends that efforts complement and coincide with the efforts of other platforms (e.g. the pan-Canadian Health Data Strategy work) to minimize confusion and avoid engagement exhaustion.

Further, the methods of communication and engagement need to speak the language of the public (i.e. lay yet inspiring language), communicating potential benefits and leveraging heightened awareness of the importance of health data as a result of the COVID-19 pandemic. The time and resources for engagement and relationship building, particularly with groups traditionally underrepresented in health research, should not be underestimated. Dedicated financial, human and time (on the order of years) resources should be dedicated to public engagement and dialogue. Reciprocity will be a critical success factor, demonstrating maximum transparency and what the public may gain from participation (e.g. the role of third parties and safeguards against data exploitation).

With a dedicated outreach process and knowledge mobilization strategy, efforts can be advanced in a manner informed by, and in collaboration with, the public they are intended to serve.

Recommendation #10: Formulate strategies and approaches, and work with complementary initiatives to address systemic, jurisdictional barriers around data sharing, administrative data linkages, privacy and risk.

The interpretation of jurisdictional laws and constitutions varies enormously across the country, creating disjointed and at times inequitable access to cohorts and related information. The WG recommends tailored strategies and approaches, syncing with other groups advocating for similar change, to bring together different jurisdictions, identify the major impediments to data sharing (e.g. existing consent agreements/parameters) and a more modern interpretation of privacy laws and potential solutions that advance data efforts with the right balance of risk and reward expected by the public. Best practices from the UK, where datasets are being linked among country-level data collections (NHS resources), large population-based studies (UK Biobank) and bespoke studies (e.g. TwinsUK) can demonstrate how such hurdles can be overcome.

As momentum around the importance of data and data sharing grows (amplified by COVID-19), continued and dedicated advocacy toward policymakers and privacy officers can ideally shift the balance and move Canada to a point where the full value of data assets is leveraged to inform clinical practice and impact the health of people living in Canada.

Recommendation #11: Secure sufficient, long-term financial commitments by communicating the value and impact of an enhanced cohort landscape in alignment with policymakers' priorities.

Policymakers' interest in health data and the life sciences has never been greater. There is momentum as well as lessons learned from the COVID-19 pandemic that have illustrated critical data gaps in our population health data environment, the importance of population cohorts and the value of data. More than ever, our data technologies (e.g. AI, machine learning) have reached a level that can unleash the power of our data. This momentum, and importantly what more can be achieved, must align with benefits to Canadians and capture the imagination of decision-makers of what may be possible. Business-grade marketing efforts that build on the perspectives of not only research but also system administration, healthcare providers, data scientists and importantly the public (**see also Recommendation #9**) to deliver a compelling story can help to unlock greater commitment.

Through a more rigorous and whole-of-community approach, a longer-term commitment can be achieved, reimagining the cohort environment as national resources that benefit people in addition to important research studies.

5. Immediate Next Steps

1. Explore the willingness and commitment among funding bodies to enhance population cohorts to understand the feasibility and degree of ambition across the Working Group's recommendations.
2. Engage with experts to rapidly perform a robust landscape assessment of cohort assets, types of data already collected, strengths and investments and expose gaps/opportunities.
3. Develop an approach to form a Coordinating Body and establish the leadership team to oversee the execution of recommendations.
4. Create more detailed action plans to execute the recommendations based on the consensus of the Coordinating Body and obtain resources to execute on the plans, particularly around engagement of the public and groups underrepresented in health research. **The WG recommends a focus on near-term or 'quick' wins to demonstrate the value and impact that can be achieved through investment in the cohort landscape, potentially in areas such as the health and wellness of Canadians post-COVID and social determinants of health.**

As Genome Canada and CIHR contemplate next steps and implementation of recommendations, WG members can be made available to act as a sounding board and offer practicable advice, leveraging our expertise and experience in the field.

6. Conclusion

The COVID-19 crisis has exposed the importance of accessing timely population-level data for evidence-based decision making, the value of rapidly generating robust data as well as the limitations of our current cohort environment and associated data linkages. With the public's heightened awareness, unprecedented levels of data being generated and the increasing power of analytical and data sharing tools, there has never been a more salient moment to create a population cohort environment that can be recognized as a national resource and is positioned to positively impact the health of Canadians. Canada's ability to remain at the cutting-edge of population health research, establish truly equitable research outputs and evidence-based policies, create a workforce in Big Data prepared for 21st-century innovations, retain investments to procure population health data within the country and advance new paradigms in medicine (e.g. precision medicine, One Health), will in part depend on a robust population cohort environment. **By setting a compelling vision and advancing the recommendations, the WG believes Canada will be on a path to success, ultimately positioning the cohort landscape to further improve the lives of people living in Canada.**