Developing an Inspiring Vision for Canadian Cancer Research

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High-Level Approach

1 *Oct – Nov 2018*

Kick-off and Stakeholder Engagement Plan Development

2 *Nov 2018 – May 2019*

Information Gathering/ Discovery Phase

3 *May – June 2019*

Analysis and Synthesis of Findings

4 *June – Jul 2019*

Vision Framework Development and Workshop

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Shift Health employed various engagement tactics to gather information from different stakeholders groups.

35 one-on-one interviews with thought leaders in the cancer research arena and beyond. Interviewees were selected to be representative of diverse geographic regions, dimensions of cancer research, the cancer care continuum, gender, and ethnicity.

7 group workshops with key informants including CCRA members, CPAC senior leadership, health economists, cancer screening leads, CAPCA, patients and Indigenous researchers.[1]

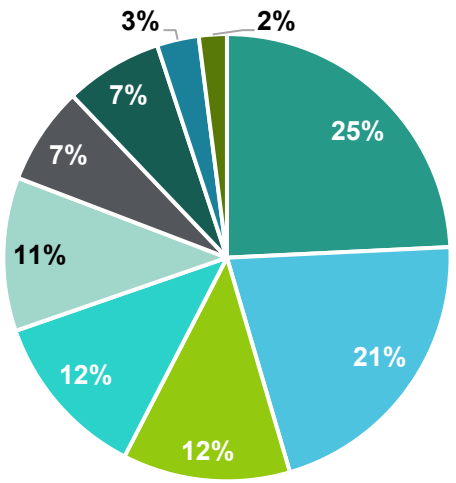
479 responses to an **online survey** distributed on May 1st to the research community, cancer societies and agencies, patient groups and the broader public (via social media).

Secondary research (e.g. peer-reviewed publications, grey literature, websites) to substantiate key findings from the interviews and gather additional data on emerging trends that may impact the cancer research field in the future.

[1] Leveraging a meeting of the World Indigenous Cancer Conference (WICC) Executive Committee Meeting in Saskatoon in February 2019.

We spoke with leaders in the cancer research arena and beyond, with representation across all pillars of health and the cancer care continuum.

Provincial Distribution of Interviewees and Workshop Participants



(n=99)

- Pan-Canadian
- Ontario
- Alberta
- British Columbia
- Québec
- Saskatchewan
- Maritimes
- Manitoba
- Newfoundland and Labrador

Pillars of Health Research *(Researchers Only)**

Biomedical	Clinical	Population Health	Health System Services
23%	35%	10%	33%

Cancer Care Continuum *(Cancer Researchers Only)**

Prevention 20% → Screening 11% → Diagnosis 9% → Treatment 46% → Palliative & End-of-life Care 9% / Survivorship 6%

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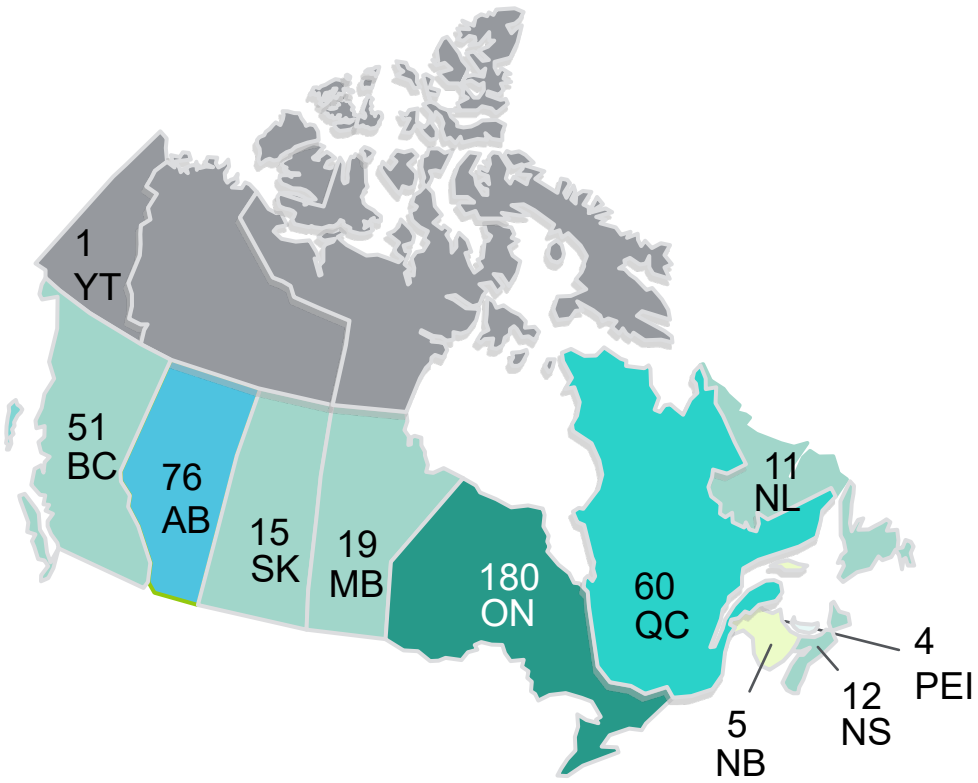
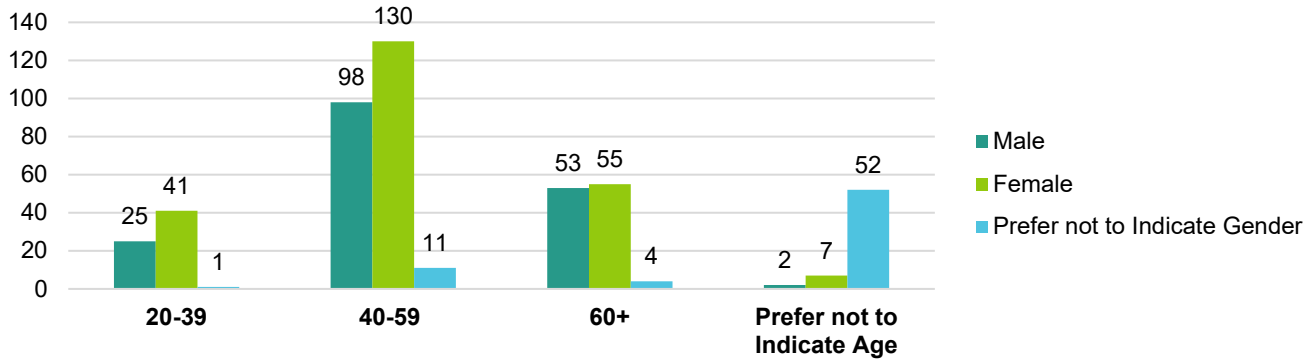
N.B. Interviews with individuals who are not involved in cancer research are not included here (22% of total number of interviewees).
* A researcher's focus area may apply to more than one pillar of health research or cancer care continuum.

479 people across the country shared their thoughts on the future of Canadian cancer research by responding to the online survey.

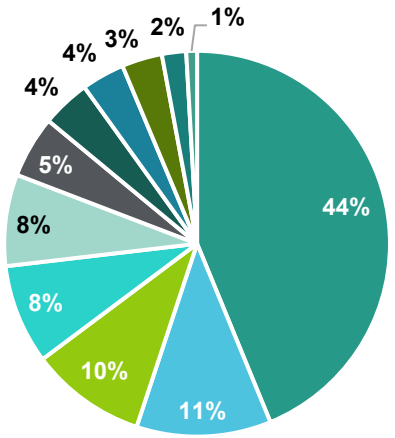
Provincial Distribution of Survey Respondents



Age Breakdown by Gender



Stakeholder Type



- Principal investigator or clinician-trialist
- Healthcare professional
- Health system or research administrator
- Person directly impacted by cancer not in research/a clinical trial
- Person directly impacted by cancer in research/a clinical trial
- Other
- Caregiver for a person directly impacted by cancer
- None of the above
- Research trainee or student
- Policymaker
- Laboratory/research technician or clinical trials unit manager

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Key Topics

From our information gathering efforts, we generally sought perspectives on the following key topics:

Trends

What are the external factors or key trends that may influence the way we do research in the future?

Strengths & Opportunities

What are we building from, what are the strengths of the Canadian cancer research system today? What are the opportunities that would further contribute to our strengths?

Principles & Values

What principles and values should be represented in our Vision for the future of Canadian cancer research?

Key Topics

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Trends	***What are the external factors or key trends that may influence the way we do research in the future?***
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Principles & Values	***What principles and values should be represented in our Vision for the future of Canadian cancer research?***

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Ten examples of emerging trends that may shape the future of cancer research.

The following emerging trends were identified from our interviews, supplemented with our secondary research and further tested and validated through the online survey.

Technology & Data Trends

- Artificial Intelligence and Machine Learning
- Genome Editing
- Automation of Research
- Real-World Evidence

Research & Healthcare Trends

- Patient Involvement in Research
- Personalized Healthcare
- Targeted Clinical Trials
- Increased Collaboration

Sociocultural Trends

- More Holistic Views of Health Research
- Demographic Shifts

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Technology & Data Trends

Artificial Intelligence and Machine Learning

Genome Editing

Automation of Research

Real-World Evidence

Example Initiatives

DeepMind

CRISPR

UniteLabs

ASCO CANCERLINQ™ Learning Intelligence Network for Quality

Cancer Researcher

*"Our **understanding of cancer will benefit from AI** …We are generating so much information everyday, we need complex information processing tools."*

*"**AI and Machine Learning will help us to stay on top of the latest discoveries** in cancer research and provide knowledge to the right people at the right time."*

Patient

Cancer Researcher

*"There will be more drugs in the future with smaller patient populations and weaker evidence. We have to **collect real-world data as we go**; health economics research will also depend more on RWE."*

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Research & Healthcare Trends

- **Patient Involvement in Research**
- **Personalized Healthcare**
- **Targeted Clinical Trials**
- **Increased Collaboration**

Example Initiatives

Count Me In

All of Us — THE FUTURE OF HEALTH BEGINS WITH YOU

Science 37 — Reimagining Clinical Research

ucb

CPHIN

Research Funder

*"In 20 years, we will see **all patients as someone we can research and learn from**. The learning research system needs to be built in a robust way to enable patient engagement and promote their participation in research."*

Industry Stakeholder

*"In 20 years it will be all about personalized medicine. There is **so much heterogeneity and so many subtypes of cancer** … the blockbluster drug is no longer the model."*

Health Economics Researcher

*"In the future cancer research will **break the silos in disciplines** and research that focus on only one cancer type. Researchers will be **collaborating** with other disease areas and across cancer types."*

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Sociocultural Trends

More Holistic Views of Health Research

Demographic Shifts

Example Initiatives

COP24 SPECIAL REPORT HEALTH & CLIMATE CHANGE

THE MILLENNIAL LEADER

wework

Research Funder

*"**Changes to the broader environment** (e.g. climate change) will have implications on research and resources as it impacts what we need to prioritize in research and funding."*

*"The **next generation of cancer researchers will be the driver of innovation**. They are collaborative and resourceful. We need to take more risks with younger people and recognize their growing role."*

Cancer Researcher

Research Funder

*"The **generational shift is a major trend**, as millennials move into decision making, it will shift what we prioritize based on their value system."*

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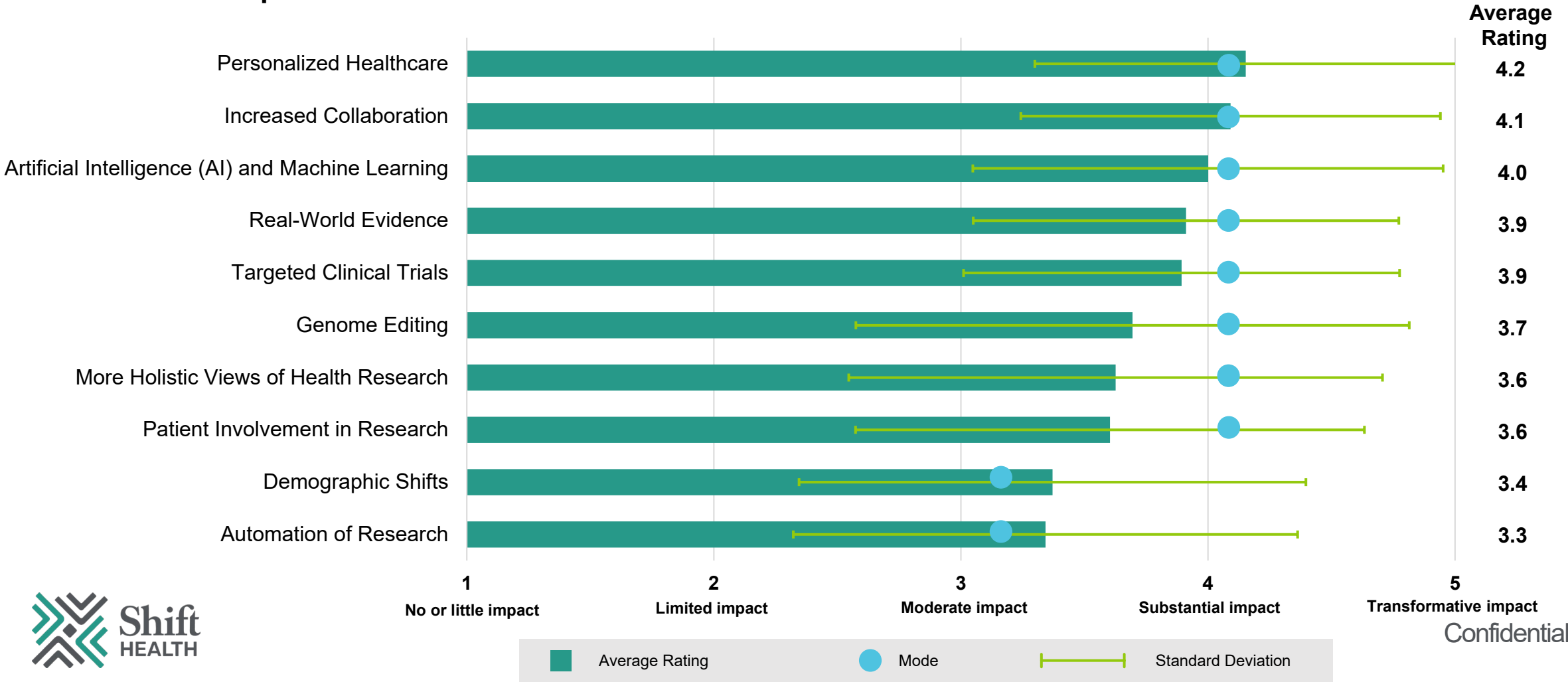
Survey respondents generally agree that these trends will have a substantial/transformative impact on cancer research in the future.

Survey respondents were asked to rate the extent to which they feel the following trends will have an impact on how researchers in Canada conduct cancer research on a scale from 1 to 5.



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While most respondents agreed on the potential impact of emerging trends, subgroup analysis highlighted unique perspectives.

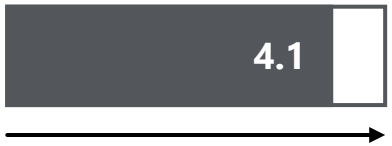
Self-Reported Knowledge of Cancer Research

Knowledge of cancer research had no bearing on perception of trends.

Patients and Caregivers

75% of patients/caregivers *(n=89)* noted that **Patient Involvement** will have a substantial or transformative impact.

Patients/caregivers rated **Real-World Evidence** among the highest across all other stakeholders groups.



(n=89)

No or little impact → Transformative impact

Healthcare Providers

76% of HCPs *(n=50)* noted that **Artificial Intelligence and Machine Learning** in research will have a substantial or transformative impact.

HCPs rated **Personalized Medicine** the highest among all other trends for its impact on cancer research.

(n=50)

No or little impact → Transformative impact

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Trends: Key Insights

- Trends such as **personalized healthcare, targeted clinical trials and patient involvement** is lending credence to the role of the individual and will continue to evolve and impact how we conduct cancer research.
- Emerging technologies such as **AI, machine learning and genome editing** are expected to have a substantial impact on cancer research and advance our ability to mine and interpret data at an unprecedented rate and scale and accelerate our scientific advances.
- Healthcare systems and how we perform research will become **increasingly dynamic as real-world evidence** is integrated and is expected to re-shape how we ask research questions, and how we prevent and treat cancer.
- The demand for a more **holistic view of health research** will require increased, broader **collaboration** with patients, the public and across research disciplines and diseases areas to incorporate the interconnections of human health with the environment.

Key Topics

From our information gathering efforts, we generally sought perspectives on the following key topics:

Trends	*What are the external factors or key trends that may influence the way we do research in the future?*
Strengths & Opportunities	***What are we building from, what are the strengths of the Canadian cancer research system today? What are the opportunities that would further contribute to our strengths?***
Principles & Values	*What principles and values should be represented in our Vision for the future of Canadian cancer research?*

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Our willingness to collaborate is seen both nationally and internationally as a hallmark of Canada's cancer research community.

*"There is a sense of a **cancer community**, everyone knows each other."*

Research Funder

Research Funder - UK

*"The collaborative nature of Canadians and cancer researchers is particularly notable … there is a **real collegial spirit** in the country."*

Cancer Researcher

*"We need **multi-sectoral collaboration** involving those with different skillsets and knowledge to come up with innovative ideas."*

BUT…

While this collaborative spirit exists among researchers in Canada, stakeholders feel that it does not always lead to the establishment of active, ongoing partnerships, nor does it involve individuals across disciplines, research pillars, and disease areas.

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We are recognized globally for our contributions to cancer research.

We are leaders in areas such as:

- **Fundamental biomedical research**, elucidating the biological basis of cancer.
- Development of **technologies/tools** to treat cancer (e.g. immunotherapies).
- **Precision medicine and personalized approaches** enabled through our excellence in **genomics** research.
- **Population-based and health services research** enabled by our public healthcare system.
- **AI and machine learning**—we are one of very few countries with a national AI strategy.

*"We **punch above our weight** in terms of investment and scale. Our cancer researchers are globally competitive and respected."*

Cancer Researcher

*"We have **world leaders** in cancer research … top notch in pediatric research.*

Caregiver

BUT…

Notwithstanding our significant contributions to the cancer field globally, our research is generally concentrated in the major centres (e.g. Toronto, Montreal, Vancouver), and discoveries are often not translated, commercialized or implemented in the healthcare system.

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The cancer research system benefits from a diverse continuum of organizations engaged in the cancer research ecosystem.

Examples of the types of organizations include:

- **Cancer patient advocacy groups, charities and foundations** amplify the patient voice and invest in cancer research.
- **Universities and Colleges** conduct research and train our next generation of cancer researchers.
- **Hospitals and academic health science centres** implement research outcomes at the frontlines of care.
- **Provincial cancer control agencies** support clinical research, provide patients with treatment options and access to novel therapies.
- **CCRA and the Partnership** coordinate national research and cancer care/control strategies.
- **Private companies** conduct R&D and invest in research infrastructure.
- **Networks** support cancer clinical research and trials.

*"How do we ensure that the Provincial Cancer Foundations are aware of what is happening at the national scene? They **generally focus locally**, which means there is a **lot of overlap**."*

Cancer Researcher

BUT…

While we have strong traditional players, there is an opportunity for greater coordination and alignment as well as the establishment of cross-sector partnerships, which will become critical in a research environment that is shifting to new models of collaboration (e.g. online platforms) and integration of new specializations (e.g. data privacy experts).

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Strengths & Opportunities: Key Insights

- While our **willingness to collaborate** is a key strength and is taking place to a certain extent within the Canadian cancer research community, there is a need to expand collaborations to other fields/disciplines, especially as research becomes more person-centred and integrated within the larger ecosystem.
- We are building from a **strong foundation of cutting-edge research**, however there is a need to elevate all pan-Canadian efforts to the frontier of research, which will in part require the entire community to take more risks to address cancer's most complex challenges.
- While investments in cancer research has established the **necessary resources**, there is a need to better coordinate and align our research efforts across the country and beyond to optimize the utilization of our finite resources and maximize the impact of research on cancer control and care.

Key Topics

From our information gathering efforts, we generally sought perspectives on the following key topics:

Trends	*What are the external factors or key trends that may influence the way we do research in the future?*
Strengths & Opportunities	*What are we building from, what are the strengths of the Canadian cancer research system today? What are the opportunities that would further contribute to our strengths?*
Principles & Values	***What principles and values should be represented in our Vision for the future of Canadian cancer research?***

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Perspectives on principles/values that should be reflected in a Vision for cancer research.

The following principles & values were identified through our interviews and further tested and validated through the online survey.

Perspectives on the Principles/Values for the Future of Cancer Research in Canada

- Patient-Centered
- Innovative
- Integrated
- Collaborative
- Sustainable
- Diverse
- Evidence/Data-Driven
- Equitable
- Translational

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20 years from now, the ideal environment for cancer research in Canada will be…

Integrated: Full integration within the health system, across the care continuum and pillars of research.

*"Canada needs to invest in complex databases and **integrated systems to maximize collaboration, data sharing and data collection**, and enable the successful implementation of cancer research outputs."*

Healthcare Professional

Collaborative: Researchers and health authorities work together across disease areas, disciplines, and international borders to share resources, knowledge and expertise.

Cancer Researcher

*"We need to **break the barriers between disciplines and cancer types**. We can't do research in silos."*

Innovative: Approaches to deliver better, cost-effective care, results in the commercialization of technologies and attracts domestic and foreign investments for health and economic impact.

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20 years from now, the ideal environment for cancer research in Canada will be…

Patient-Centered: Persons affected by cancer are full partners in determining the research agenda, ensuring research is meaningful for patients, and assuring that treatment and care options are tailored to the individual.

*"Research is **increasingly based around patients and patient material**. We need to build our scientific workforce around this."*

Research Administrator

*"We need to take a more **sympathetic approach with research** and realize that we as patients aren't numbers, we are people."*

Patient

Evidence/Data-Driven: Use of data and real-world evidence to make better decisions on the treatment of and impact of cancer care on health outcomes.

Cancer Researcher

*"The paradigm of a learning health system needs to be reformulated. **Foundationally it's about using data to make better decisions in healthcare**."*

Translational: Research results and knowledge rapidly move into and are adopted within clinical practice, healthcare services and prevention programs to address needs within the healthcare system.

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20 years from now, the ideal environment for cancer research in Canada will be…

Equitable: Improved access to cancer care services and treatment for all individuals (e.g. ethnicity, gender, geography) and research system supports equity (e.g. in funding decisions).

Diverse: Canada's diversity, including underserved, Indigenous Populations and vulnerable populations is represented in our databases, research designs and clinical trial studies.

Sustainable: Research system is properly resourced both financially and in human capital needed to operate most effectively.

Policymaker/ Caregiver

*"One of the many challenges will be to ensure that the **research results are representative of the growing Canadian population**. To date, most of the research ignored the ethnicity/race and sociocultural aspects that can play a huge role in any patient's journey."*

Cancer Researcher

*"We need to better harness our human capital, infrastructure and financial resources to ensure that we **do not leave anyone behind**. We need to broaden the bridges, build a sustainable foundation, ensure there is accountability, and **be prepared to walk together, always**."*

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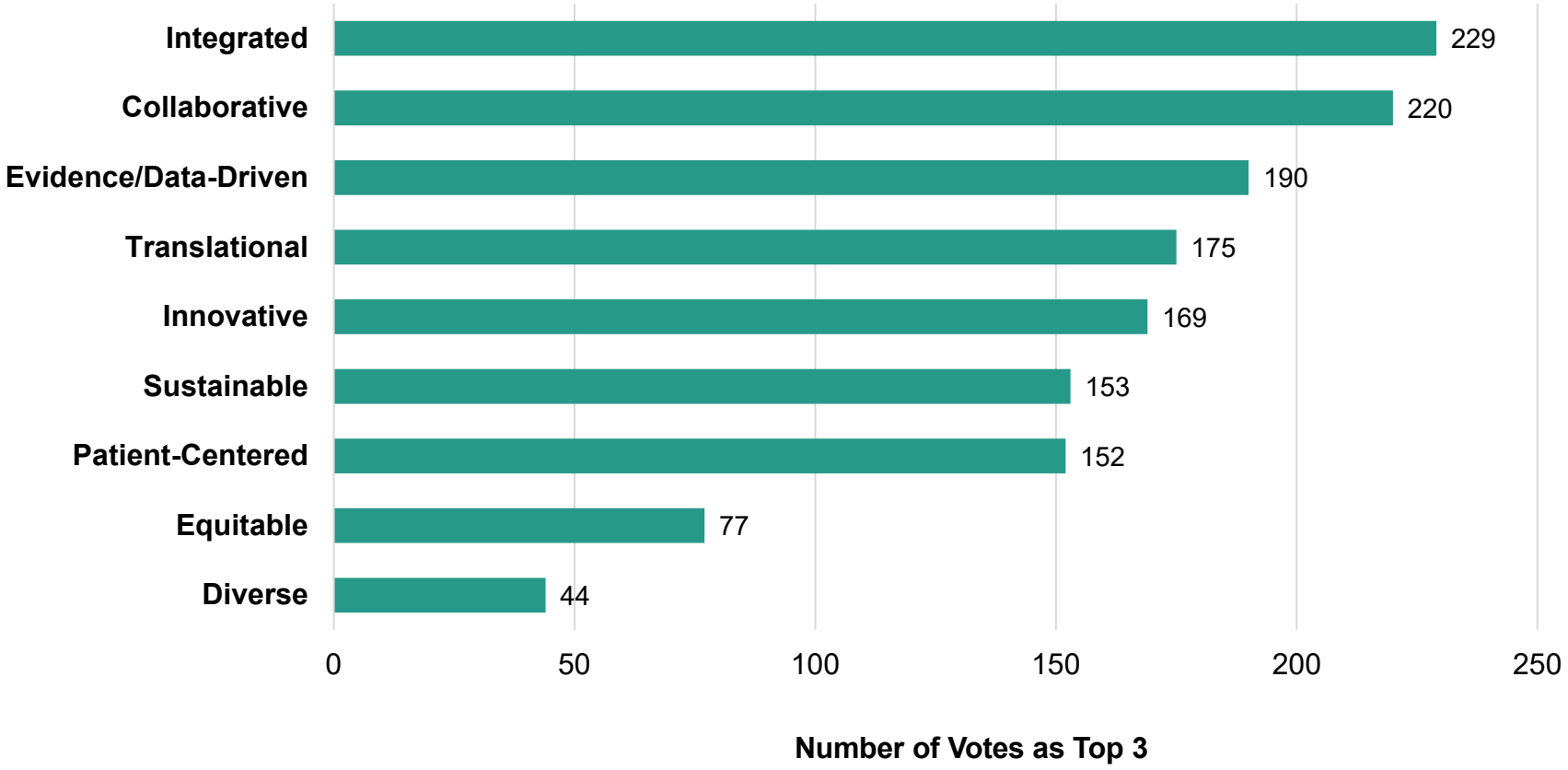
Survey respondents generally agree that most of the values/principles should be used to describe the future of cancer research in Canada.

Survey respondents were asked to select 3 values/principles that they would like to see reflected in the Vision.



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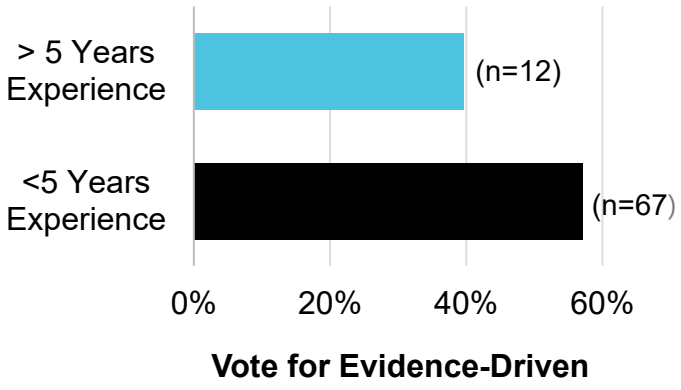
While most survey respondents agreed on the values/principles for cancer research, subgroup analysis highlighted unique perspectives.

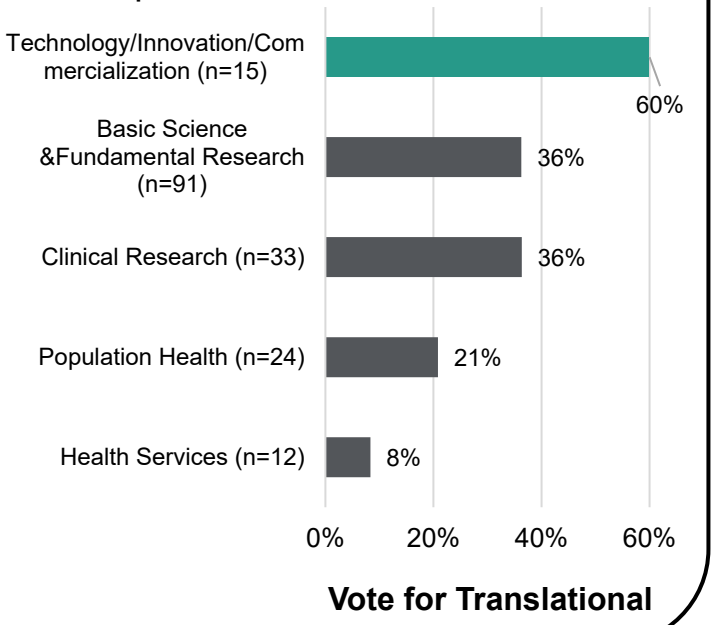
Early-career Investigators

Ranked **Evidence-Driven** higher than experienced PIs.



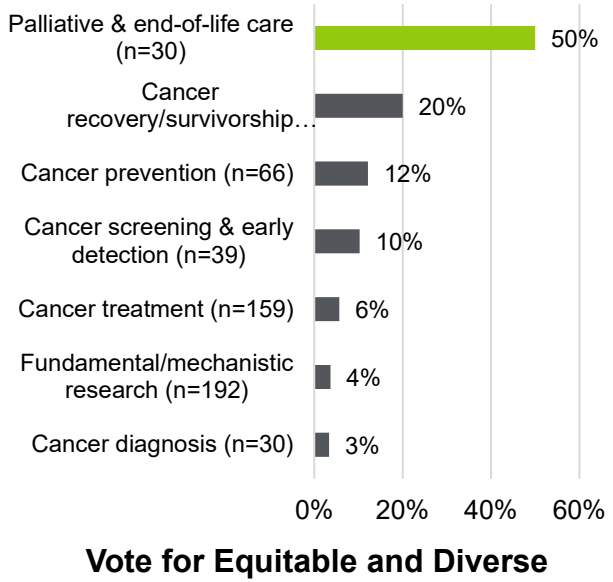
Tech/Innovation/Commercialization-Focused Researchers

Ranked **Translational** higher than any other researcher focused on the different pillars of health research.



Palliative and End-of-life Care Researchers

Ranked **Equitable and Diverse** higher than any other researcher along the cancer care continuum.



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Principles & Values: Key Insights

- Leaders in cancer research and the majority of Canadians agree that our future cancer research system needs to be **collaborative** and fully **integrated** within the health system; the Vision needs to inspire new approaches to collaboration across disciplines, and emphasize the **translation** of discoveries into innovative solutions for cancer care and control.
- The application of **evidence- and data-driven** research to inform best practices will become increasingly important, especially as the next generation of cancer researchers advance their careers; the influx of data will require a system that promotes **data privacy** to protect the individual, and the **use and digitization of evidence** to take full advantage of data in improving health outcomes.
- Canadians value **patient-centredness, equity and diversity**; the Vision should embrace our **population** and **promote health and equity for all**, by placing the individual at the centre of all research initiatives.

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