## Canadian Cancer Society

Key Findings and Preliminary Considerations Report


Dr. Chris Delvecchio
Principal

Dr. Marni Williams
Senior Consultant

Dr. Helen Luck Consultant

Dr. Kevin Szkop
Analyst

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## Project Impetus

Given the recent developments in the cancer research environment, including the new CCS strategic plan, the Canadian Strategy for Cancer Control and the Vision for Cancer Research, CCS has engaged Shift Health to support the development of a research strategy that will guide the organization's related activities over the next 5 years.

CCS' new strategy will provide a framework for decision-making to further strengthen cancer research in Canada and enable CCS to continue to serve as a critical catalyst in the advancement of cancer care through research.

## Project Approach

January; Ongoing

## Kick-Off \& Project Management

- Facilitate a kick-off meeting to formally initiate the project.
- Identify potential benchmark organizations and stakeholders for consultations.
- Support the CCS Project Team in validating the analysis and survey
approach of the researcher and nonvalidating the analysis and survey
approach of the researcher and nonresearcher surveys.

Late-January - April
May - June

- Surveys-Conduct qualitative and quantitative analysis of researcher and nonresearcher survey responses.
- Benchmarking-Benchmark 5 research funding organizations (completed by CCS Research Team).
- Consultations-Conduct one-on-one and group interviews with internal and external stakeholders.
- Develop a report to summarize the key findings.

Deliverable: 'Interim Key Findings Report'

- Leverage primary and secondary research to develop a strategic framework that outlines a research mission, strategic commitments, goals, activities and anticipated impact.
- Build on the strategic framework to develop the full research strategy.

Deliverables: CCS Strategic Framework'; 'CCS Research Strategy'

## Overview of CCS' Research Program

## Research at CCS: Background

## CCS' purpose is to unite and inspire all Canadians to take control of cancer.

- Vision: To champion world-leading outcomes in cancer prevention, treatment and support.
- Mission: In partnership with donors and volunteers, to continuously improve impact through cancer research, advocacy and support services.
- Goal for Research: To fund a deliberate portfolio of scientifically excellent, high-performance research that improves cancer outcomes and addresses greatest opportunities for progress, while providing recognition to CCS, leveraging partnerships and meeting donor interests.


## Funding Activities

- Funding Mechanisms: CCS' peer-review process ${ }^{1}$ leverages the expertise of diverse scientific leaders who oversee research funding, grant review and funding recommendations, as well as patients/survivors with lived experience, and scientific officers.
- Funding Opportunities:
$\diamond$ Flagship grants (e.g. Innovation, Innovation to Impact, Impact)
$\diamond$ Partnership grants (e.g. Survivorship Grant, Spark Grants, Metastatic Breast Cancer Dream Team)
$\diamond$ Infrastructure (e.g. ARCC, CCTG); Commercialization (e.g. CDL-Cancer), travel and special grants (e.g. prevention, QoL).


## Mission Activities

- Patient education: Including websites with information about cancer prevention, screening, personalized medicine and clinical trials.
- Advocacy: Including improving access to drugs, caregiver support, palliative care, and ensuring continuous support for cancer patients throughout the COVID-19 pandemic.
- Outreach: Including engagement of community members to participate in grant panels, research trainee opportunities (e.g. CCS RIOT), fundraising and community events.
- Fundraising: Including hosting of fundraising events, most of which are currently virtual due to COVID-19.

[^0]
## Research at CCS: Breadth of Funding Support

CCS is the largest national charitable funder of cancer research in Canada, dedicating ~\$40M per year to the most promising cancer research across many cancer types and geographical regions in Canada.

## Distribution of CCS Funding Across Cancer Types



Geographical Distribution of CCS Funding


## Research at CCS: Select Highlights

## Canadian Cancer Trials Group (CCTG)

CCS is a founder and key supporter of the national clinical trials network, CCTG, and has invested a total of $\sim \mathbf{\$ 1 1 0 M}$ in funding to date to the group. The support of CCS has led to the success of CCTG in conducting high-impact cancer clinical trials in $\sim 90$ communities across Canada with $\boldsymbol{> 1 7 , 5 0 0}$ patients, testing $\mathbf{> 2 0 0}$ potentially life-saving drugs, and has led to the approval of $\mathbf{1 3}$ new cancer drugs.

## ComPARe Study

The CCS-Partner Prevention Research Grant funded the ComPARe study, which brought together academic teams and cancer organizations across Canada in cancer epidemiology, biostatistics, cancer risk factors and knowledge translation. The study found that 4 in 10 cancer cases are preventable through healthy living and policies that protect the health of Canadians, led to 21 peer-reviewed publications with diverse knowledge applications and helped to inform and target future prevention research and policies.

## Canadian Centre for Applied Research in Cancer Control (ARCC)

CCS is a founding and funding partner of ARCC, a pan-Canadian research network that specializes in applied research that informs policies and practices to achieve equitable, sustainable and efficient cancer care for all Canadians. CCS' support for ARCC has contributed to the creation of Canada's first lung cancer screening program in BC and the extension of HPV vaccination program to include all children across Canada.

## Survey Findings

## Researcher Survey: Demographics



## Location ${ }^{2}$



* Quebec and Nova Scotia have nearly proportional representation


## Researcher Survey: Demographics (Continued)



## Funding Status



- Funded (PI/Co-PI)
- Not funded (PI/Co-PI)
- None of the above


## Overall, the majority of the researchers agree that CCS' key funding programs are a worthwhile investment for CCS.



## Most researchers attribute limited funding opportunities and lack of long-term funding as the biggest challenges facing cancer research in Canada.



## Overall, respondents most value that CCS funds a diverse cancer research portfolio, its well-respected peer-review process and its support of ECRs.



## Researchers believe that CCS can maximize research impact by supporting ECRs, high-risk/high-reward research projects and multidisciplinary efforts.



## There is generally a lack of consensus in prioritizing a specific research area or areas.



## Researchers suggested many opportunities for CCS to further support the research community.

## Prioritize Discovery Research

Focus on
Underrepresented Populations

## Support Capacity

 Building \& Knowledge TranslationIncrease Advocacy and Partnership Efforts

- Recognizing that the majority of survey respondents were biomedical researchers, many respondents communicated that CCS should prioritize funding of fundamental or discovery research over implementation or translational research.
- The need to fund research conducted by and with underrepresented populations (e.g. Indigenous communities, immigrants, rural/remote communities) was highlighted by some researchers.
- Respondents highlighted that CCS could promote funding initiatives to reduce research silos, facilitate networking (e.g. conferences, panel discussions), and support knowledge translation and mentorship programs within funded cohorts.
- Researchers suggested that CCS can advocate for increased funding from federal and provincial governments, and facilitate partnerships with other cancer funding bodies, industry (e.g. pharma) and government.


## Researchers suggested many opportunities for CCS to further support the research community, Continued

## Increase Public Education and Involvement

- Improving public outreach and communication efforts (e.g. to advertise high-impact publications by CCS-funded researchers) was desired by researchers, as was the continued involvement of patients and survivors in CCS research funding processes.
- Implementing mechanisms to increase the diversity of the funded researcher pool (e.g. geographically and culturally diverse review panel, considering barriers affecting research timelines for underrepresented researchers, and a double-blind review process) and continued training opportunities (e.g. scholarships, fellowships) were highlighted by survey respondents.
- Funding and support towards the collection, distribution and accessibility of cancer research data resources and the need to create a data strategy was mentioned by researchers.


## Non-Researcher Survey: Demographics



## Respondents prioritize research on early detection, treatment and more immediate, effective and safer cancer treatments.

## Allocation of \$1M research funding across care continuum



- Early detection and diagnosis
- Treatment
- Prevention
- Cancer recurrence and metastasis (spread)
- Quality of life for survivors
- End of life



## ~75\% of respondents believe it is important to keep research dollars in their local university, hospital and community.

Importance of spending cancer research dollars in local community (at your closest university or hospital)


- Very important
- Somewhat important
- Somewhat unimportant
- Not important at all
- I'm not sure

While there were no major differences across the different types of survey respondents (70-74\% for all groups) ${ }^{1}$, geographic differences did exist for respondents from Saskatchewan (88\%), Manitoba (81\%) and Alberta (81\%) who want to keep cancer research dollars local more so than those from Quebec (73\%), Ontario (72\%), BC (72\%). ${ }^{1}$

The majority of respondents are interested in learning about CCS' research impact and prefer to be engaged in setting research priorities. Notably, a large proportion are uninterested in participating in any of the proposed activities.

Interest in learning about CCSfunded research outcomes


Types of Engagement/Involvement Preferred


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## Key Takeaways

- The breadth of funding across cancer types is valued. As an organization designed to support all Canadians, stakeholders agree that all cancer types must remain in scope, co-funding with partners, where possible, and addressing remaining gaps/unmet needs.
- There are somewhat opposing opinions between researchers and the public regarding funding along the research continuum. Researchers value foundational research (e.g. basic or discovery science) while non-researchers appreciate more immediate, translational research (e.g. quality of life, health services research). CCS will need to help bridge the divide and balance its limited funding dollars across high-risk, high-reward (but longer-term) research with more applied research that can deliver nearterm impact.
- Researchers and non-researchers agree on the importance of prevention and early interception. Early detection and diagnosis, and to some extent prevention of cancer, were identified as areas in need of funding. These areas currently have the lowest research investments in Canada ${ }^{1}$ and with greater focus, a significant impact can be made for all Canadians.
- There is a need to place the patient (or people) at the heart of research efforts. Key priority areas identified by researchers like precision medicine will only be enabled by further emphasizing patient-centred research, which spans the spectrum of research types, will require education and building awareness among the public (as identified by researchers) and aligns with the increasing person/patient-oriented nature of prevention, detection and treatment efforts.


## Key Takeaways, Continued

- The engagement and representation of diverse stakeholder groups in cancer research is a critical challenge. CCS needs to improve representation of specific researchers (EDI, ECR), patients with specific cancer types (hard-to-treat, poor survival cancers) and population groups (pediatric and AYA, Indigenous communities) within its research program. Given the low public interest in being engaged in CCS' research activities, education on the different opportunities and types of participation in research as well as the importance of engagement in research is needed.
- CCS' well-respected, rigorous approach to peer-review is highly respected by researchers. The research community will expect that CCS continues to uphold this high standard in selecting and funding research excellence (see next point).
- The desire of donors to keep funding dollars local cannot compromise standards. In addition to educating donors that research has no boundaries, CCS can invest in strategies that promote trans-regional research teams and knowledge mobilization of research impact across Canada. These investments will allow CCS to continue to fund the best research, keep donors engaged and maintain a level of integrity that is so highly recognized by the research community.
- Sustainable funding for cancer research is a critical priority. Given the challenges with competition for scarce funding, major disruptions due to COVID-19, and grants that have a limited timelines or are non-renewable, CCS can focus efforts on expanding the cancer research funding envelope through national/international partnerships with (international) cancer organizations, other charities, industry and organizations outside of health (e.g. entertainment and media, finance).


## Consultation Findings

## Interview Questions and Stakeholder Types

A total of 74 stakeholders across diverse areas of expertise were engaged through individual or group interviews.

Type of Stakeholders Interviewed ( $\mathrm{n}=74$ )


## Topics Covered in Interviews

1 Enduring Strengths and Accomplishments
2 Current Challenges Faced by CCS
Trends in Research, Cancer and the Charitable Environment

4 Opportunities (Funding and Beyond)
Alignment with the Canadian Strategy for Cancer
Control and Canada's Vision for Cancer Research

## (1) Enduring Strengths and Accomplishments ${ }^{1}$

- Supporting a Wide Breadth of Cancer Research. Many stakeholders noted that CCS uniquely supports cancer research across dimensions (e.g. basic, clinical, psychosocial), the cancer care continuum and cancer types, some of which are not traditionally supported by other major funders.
- Trusted Organization with a Prestigious Reputation. CCS is a trusted and reputable national organization; CCS grants are regarded as highly prestigious within the cancer research community, and fundraising events and support services are well-known to the cancer community.
- Rigorous Peer Review Process. Various stakeholders noted that the CCS research program is well-recognized for its rigorous approach to peer review and for funding excellence in cancer research.
- Consolidated Cancer Research Funding Landscape. The amalgamation of cancer research funders by CCS (e.g. CBCF and PCC) has resulted in the consolidation of funds and reduced inter-charity competition.
"CCS has outstanding name recognition in Canada. A known and trusted name in cancer research.
${ }^{\text {"Providing funding to the best research }}$ is CCS' greatest strength, as well as funding all types of cancer throughout country.'

$$
\begin{array}{cl}
\text { "Bringing in CBCF and PCC was a } & \\
\text { good move-the landscape was } & \\
\text { previously very fragmented and having } & \\
\text { too many funding sources can be } & \text { Cancer Org./ } \\
\text { confusing to researchers." } & \text { Gov. Agency }
\end{array}
$$

Researcher



## Frequently reported successful CCS funding/assets include:

- CIHR/CCS Survivorship Team Grants
- Canadian Population Attributable Risk of Cancer (ComPARe) study
- Canadian Center for Applied Research in Cancer Control (ARCC)
- Canadian Clinical Trials Group (CCTG)
- CCS/CIHR/BC SPARK Grants
- Innovation, Innovation to Impact, and Impact Grants
- Annual Canadian Cancer Statistics Reports


## 2. Current Challenges Faced by CCS¹

- Effective Communication of Research Progress and Outcomes. Many stakeholders are unaware of CCS' research objectives, activities and importantly, measurable impact due to the lack of effective communication and storytelling with the broader community.
- Managing Donor Expectations. CCS lacks sufficient mechanisms to actively match donors to specific research initiatives, creating a challenge for the management of donorrestricted funds and losing out on opportunities to increase funding dollars.
- Regional Localization of Research Funding. "Funding the best research" often skews funding towards comparatively well-resourced regions (e.g. ON, BC, QC); research dollars fundraised in less research-intensive regions are not returned to local researchers.
- Transparency in Grant Distribution. Researchers and donors are unclear on non-project specific criteria (e.g. career stage, research area, EDI factors) that are considered by CCS during decision-making on the allocation of research funds.
- Limited Funding Dollars. Low funding success rates due to limited funding dollars and a highly demanding application process deters researchers from applying to CCS grants.


## 2) Current Challenges Faced by CCS¹, Continued

- Consistent, Meaningful Patient Engagement in Research-related Activities. CCS struggles with consistent and meaningful outreach to patients and in ensuring meaningful involvement of patients in setting research priorities, funding decisions, and sharing their lived experiences with researchers and the broader community.
- Sustained Researcher Support. CCS-funded researchers and leadership communicated that CCS lacks continued involvement and research progress


## "CCS needs to connect more with their

 award winners by building in project checkpoints, and making sure stakeholders get updates throughout the projects, and not just at the end." support during the funding period, especially for ECRs.- Negative Perception within Pediatric and Adolescent/Young Adult Cancer (AYA) Communities. The pediatric/AYA communities are hesitant to be reengaged by CCS due to perceived lack of authentic support from CCS and previous outreach that was deemed to be opportunistic.


## 3 Emerging Cancer Research Trends ${ }^{1}$

- Screening and early detection—Noted to be a significant area of increasing interest for adults-but not pediatrics or AYAs.
"Research is focusing more on involving patients as research partners from the outset.
"Burden of survivorship is an emerging trend. We've been so focused on cure, immediate Qol during treatment, and rarely recognizing that we have a huge population of survivors. This is especially important for youth, as they have a long time to live after cancer."


## "There is a huge opportunity to

 expand further into cancer prevention through both education and research."
## 3) Emerging General Research Trends ${ }^{1}$

- Data and Advanced Analytics—Including AI/machine learning/wearable technology used in research, early diagnosis, improved treatment, and expedited care in real-time.
- Rise of Virtual Care—Transition to virtual care post-COVID-19 that will result in greater access to care (e.g. innovative treatments via clinical trials) for remote populations.
"CIHR has prioritized Indigenous health - for example, how is climate change in Northern Canada linked to increased cancer rates?"

Cancer Org./
Gov. Agency

- Research in Underrepresented Populations—Research focused on reducing health inequities and cancer data gaps in Indigenous, marginalized, and lowincome populations, women and pediatrics/AYA.
- Multidisciplinary Research-Increasingly complex research questions being addressed using team science and collaboration to achieve innovative, bold, and holistic solutions.
"Data collection and research within Indigenous populations is a Canada-wide issue. CPAC is conscious of this and is engaging Indigenous partners about data governance."

Partner Organization

## (3) Emerging Trends in the Charitable Environment ${ }^{1}$

- Donor Composition and Behaviour. Major gifts from high net-worth donors are increasing in the research charity landscape. Additionally, major donors want to be involved in deciding where their dollars are going (e.g. specific regions, cancer types, researchers or institutions) and are less willing to contribute to open competitions that lack clearly defined ROIs and tangible impact.
- Digital and Disruptive Fundraising. There has been a greater reliance on online fundraising during COVID-19 due to the inability to hold in-person events (e.g. galas, walks/runs), as well as novel outside-the-box collaborations (e.g. with entertainment and media industries).
- Non-Traditional Funding Models. Charities are exploring innovative funding models and ways of engaging donors such as crowd/collective funding, venture philanthropy, and grassroot fund matching.
- Inter-Charity Collaborations. Charitable funders are becoming increasingly open to sharing assets and engaging in mutually beneficial and strategic partnerships that are focused on achieving a common goal.
"Bigger donors want to be more involved in what they are funding and are less willing to put money in an open competition. The current CCS process makes this very difficult, since there is no mechanism to connect donor desires with specific researchers/projects across the country.'

CCS Leadership
"Smaller donations are continuing to dry up as regional offices close, giving rise to a shift towards donor-focused gifts; this trend will continue and will change how people donate research funds."


Cancer Researcher

## 4) Opportunities ${ }^{1}$ (Funding)

- Risk Diversification of the Funding Portfolio. CCS can create a more diverse funding portfolio that continues to support its annual open competitions but also dedicates a meaningful percentage of funds towards piloting more rapid, innovative, interdisciplinary and high-risk/high-reward competitions (e.g. SPARK Grant, SU2C Convergence Grant, X-Prize, collective funding mechanisms).
- Targeted Funding Competitions. Recognizing the importance of maintaining the breadth of research that it supports, CCS can also offer targeted funding opportunities in identified areas of greatest unmet need (e.g. ECR support, underrepresented groups, psychosocial, emerging data-based projects, ped/AYA research, and region-specific grants much like the Atlantic Cancer Campaign).
- Improving Communication of Impact. CCS can better communicate its impact through:
$\diamond$ Defining clear research goals and reporting measurable, tangible research outcomes.
$\diamond$ More deliberately translating the impact of CCS-funded research on local communities, especially in smaller regions (e.g. prairies, Atlantic Canada) where presence has declined.
$\diamond$ Leveraging enthusiasm of funded researchers and people with lived experience to share their stories on how the CCS-supported research has impacted their lives and communities.

Shift
HEALTH
${ }^{1}$ Bullets are ordered from most to least frequently mentioned findings. SU2C: Stand Up 2 Cancer.

CCS Leadership
"CCS shouldn't be catering its research priorities to what researchers want, it should be driven by outcomes and CCS mission."
"Targeted research opportunities where CCS can be the sole funder will open the door for major gifts and increase a sense of pride that CCS has funded a large, recognized project."
"CCS can have more opportunities for the research community to be involved in raising awareness with the public. Researchers are happy to talk to potential
major donors, too."

Confidential• 33

## 4. Opportunities ${ }^{1}$ (Beyond Funding)

- Co-Funding Opportunities. CCS should continue to seek partners with local and international agencies (e.g. SU2C, ACS) with aligned interests through creative matched funding mechanisms or innovative project-based initiatives that are mutually beneficial (e.g. methodology research).
- Facilitate Collaborations within the Cancer Research Community. CCS can be a natural liaison between researchers and those within CCS' expansive national network (e.g. patients, advocates, KT experts, mentors, investors) by actively fostering innovative collaborations (via multi-stakeholder interdisciplinary research summits, networking platforms).
- Greater Integration of Patients in CCS' Research Activities. With a deep connection to the cancer community, CCS needs to increase the representation and engagement of patients in its research activities (e.g. priority setting, grant reviews, program design).
- Donor Engagement and Education. Taking a proactive approach to managing, educating and directing donors to existing research opportunities that match their interests will allow CCS to maximize contributions from donors.
"You need a lot of patients to provide a wholesome opinion meetings with researchers should have equal numbers of patient and researchers."

Patient/Survivor
"CCS should involve more patients in their grant funding decisions and use lay language to increase accessibility."
"Fundraising and research funding should be highly connected. Engagement with donors for research needs to be tailored to their interests.

CCS Leadership

## 4) Opportunities ${ }^{1}$ (Beyond Funding, Continued)

- Partnering for Research Commercialization. Given CCS' resource constraints and limited expertise in commercialization, CCS can explore partnerships with leaders in this space (e.g. FACIT, MaRS) and provide support to funded researchers on an ad hoc basis.
- Address Critical Need in Pediatric and AYA Communities. CCS is well-positioned to fill a critical leadership gap in the pediatric/AYA communities in Canada. CCS can:
$\diamond$ Collaborate strategically with trusted organizations in this space (e.g. directed research funds managed by C17 or 3CTN, improving access to clinical trials).
$\diamond$ Raise national awareness on the largely unmet and distinct research needs of ped/AYA (e.g. ped/AYA annual cancer statistics, oncofertility, QoL impact across lifespan).
$\bullet$ Exchange knowledge and best practices between ped/AYA and adult cancer research communities (e.g. ped/AYA strengths in storytelling, facilitation of smaller clinical trials).
- Integration of Research Across CCS. Breaking down silos and working closely with other CCS teams will allow the CCS research team to maximize on available internal assets and impact on the research community (e.g. create data repositories accessible to researchers, launch research-oriented fundraisers, advocate for access to critical research innovations).
"CCS has the critical mass and ability that few other groups have to lead and be the quarterback for the field of pediatric/AYA."

Ped/AYA Stakeholders
"We should internally leverage CCS infrastructure in unique ways; we see people applying for funding to do things that CCS is already doing/has done; internal work at CCS is a wellkept secret due to working in silos."

CCS Leadership

> "CCS should encourage funded researchers to move into the commercialization space. This would be a positive new area-but not a main event for CCS."

## (5) Alignment with the Canadian Strategy for Cancer Control (CSCC)

Overall, CCS is seen as a contributor to all priorities in the Canadian Strategy for Cancer Control to varying degrees, and stakeholders supported further alignment between CCS research and the CSCC.


Reduced risk of getting cancer and improved diagnosis. Most stakeholders saw the most alignment between CCS, Priority 1 (reducing risk of getting cancer) and Priority 2 (improved diagnosis and early screening), though members of the pediatric and AYA cancer communities highlighted that these areas of research are least applicable to young persons with cancer.

Elimination of barriers to care and delivery of information. Patients, survivors and advocates saw alignment between these strategic priorities and CCS' support for health services research, broader advocacy and information support services (e.g. reducing barriers to access to innovative drugs and clinical trials, especially for pediatric/AYA groups).

HEALTH

## (5) Alignment with Canada's Vision for Cancer Research

Stakeholders were aligned with Canada's Vision for Cancer Research, noting a desire for CCS to be a part of the 'bold movement' for cancer research. Some stakeholders highlighted that CCS plays an important role in the commitment towards "Activated Populations".


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## Key Takeaways

- CCS can be a greater enabler of research outside of grants/funding competitions. While CCS is well-recognized by the research community as a major funder for cancer research, there is a desire for CCS to further support the research community beyond traditional mechanisms. CCS can leverage its network to spearhead national initiatives (e.g. data repositories, Canada-wide research summits, networking platforms) to connect diverse members of the community to collectively advance research.
- With its reach and connection, CCS is ideally positioned to help activate populations for research. In order to enable trends like personalized medicine and patient-centred research, the public needs to be involved. In alignment with the Research Vision, CCS can play a role in enhancing scientific literacy, leveraging its trust and engaging in an authentic and effective manner to elevate the voices of researchers and patients. In part, communicating the impact of CCS' researcher activities will contribute to a more aware and activated public.
- CCS can integrate research more directly within its larger corporate mission. The research team is seen by some as being siloed from other programs at CCS, which means that research-related activities may not be benefitting from other programs and vice versa. CCS' research team needs to work more closely with other programs to ensure research is top of mind when planning CCS initiatives (e.g. fundraising, donor engagement, advocacy and information support activities), better align internal efforts, reduce duplication and advocate for research funding and research participation.


## Key Takeaways, Continued

- Research with the potential for the greatest impact should be prioritized. CCS' limited research funding envelope makes it impossible to address the needs of all stakeholders (e.g. across geographics, patients/survivor of varying age groups, cancer continuum, cancer types, donor types). In alignment with its reputation of funding the best research, CCS will need to prioritize funding toward areas with the high degree of (or potential for) impact for Canadians, ideally in alignment with national cancer strategies (e.g. CSCC).
- CCS can embrace more diverse funding/fund raising mechanisms. The charitable environment is increasingly moving towards digital fundraising, greater percentage of high net worth donors, innovative/non-traditional models to funding research (e.g. collective funding, more rapid, high risk/high reward competitions). CCS too will need to embrace diverse mechanisms to raising and granting research funds while maintaining its strength in scientific rigour and funding research excellence.
- Establish strategic partnerships to promote research translation and commercialization. Given limited resources and expertise in some areas, CCS should leverage mutually beneficial strategic partnerships with other organizations that are already active in areas such as clinical trials support (e.g. C17) and commercialization (e.g. FACIT, MaRS, C3i). This may also avoid conflicts of interest and any negative perceptions around for-profit endeavors.


## Benchmarking Findings

## Overview

Five leading international charitable organizations that are dedicated to supporting research in cancer or other disease areas were studied to gather information on best practices in funding approaches, community engagement, knowledge translation, commercialization and partnership/collaborations. The organizations include:
KWF
KANKER
BESTRIJDING
KWF (Dutch Cancer Society)

Cancer Research UK (CRUK)

Multiple Myeloma Research Foundation (MMRF)

Alex's Lemonade Stand Foundation (ALSF)

## Michael J. Fox Foundation (MJFF)

## MJFF supports Parkinson's Disease research through open as well as targeted research grants, research-led nonfinancial initiatives and community engagement in research.

## Research Funding

MJFF funding programs support individual projects and address field-wide challenges through consortium driven solutions:

- Annual Core Funding Programs: Intentionally open-ended grants for novel and iterative ideas across the spectrum of Parkinson's research.
- Targeted Funding Programs: Requests for applications that address a specific gap in understanding or patient need, identified by in house team, business strategists and PD experts.
- Supplemental Funding: Add-on funding for projects that show significant progress and continued potential as determined through MJFF's built-in milestones that provide opportunities to troubleshoot and track research progress.


## MJFF-Led Research Initiatives

MJFF provides vital non-financial resources for Parkinson's researchers:

Parkinson's Progression Marker's Initiative: In partnership with $>30$ pharma companies, non- and for-profit funders, this flagship study aims to develop a holistic understanding of PD; has been accessed by researchers >1.7M times since 2010.

Fox Insight: Foundation-driven initiative in partnership with 23 andMe that that has collected >47K patient-reported and genetic data and has been made available to researchers.

- Fox Trial Finder: Serves as a vital link between the patient community and researchers by sharing information on clinical trial participation and connecting them to trials that need volunteers.


## Community and Donor Engagement

 MJFF provides opportunities for patients, donors and the broader PD community to be involved in research and its funding:- Patient Council: Established in 2009 as a formal channel to gather input from PD patients and the broader PD community to ensure that the MJFF "always has the patient voice in mind".
- Team Fox MVP Awards and Dinner: An annual event recognizing and celebrating contributions of top Team Fox grassroots fundraisers. Industry collaborators are invited to purchase tickets.
- MJFF Podcasts: Showcases scientists, doctors and people with PD discussing aspects of life with the disease, and research toward breakthroughs.


## KWF (Dutch Cancer Society)

## KWF supports the translation of research through interdisciplinary teams and new funding programs to achieve their goal of improving cancer prevention, treatment, and the quality of life of patients and survivors with all forms of cancer.

## Research Funding

To ensure that its funded research is fast-tracked to practical applications, KWF has a funding portfolio that prioritizes knowledge translation and collaborations. Programs include:

- Research Consortium: Funding for research projects performed by more complex and/or bigger collaborations involving multiple research institutes and for-profit partners
- Funding in Tracks: Allows for the definition of the scope of each research project, and classifies proposals based on the Exploration, Development, Implementation research phases.
- Varied Types of Funding: Allows researchers to apply to the type of funding more applicable to their project, including limited-scope research projects, projects led by early-career researchers, unique high-risk/highreward projects and infrastructure initiatives.


## Research Translation Support

KWF is a sponsor of the Oncode Institute, an independent entity that:

- Unites >800 scientists, policy makers, and investors under a single strategy to understand cancer and translate research into practice.
- Performs vital basic research and is specialized in cooperating with third parties to guide its scientists' discoveries towards translational and clinical research and novel diagnostics, drugs and treatments.
- Employs a dedicated team of commercialization experts with oncology, scientific and business experience to work with research groups to proactively identify and activate commercialization opportunities.
- Has grown since 2018 from 43 to 62 Oncode Investigators, from 9 to 12 partner institutions (e.g. academic, research institutes, medical centers), and has successfully launched a spin-off company.
- Prioritizes the voice of the patient through patient representatives on the Oncode Clinical Advisory Board and Supervisory Board.


## Cancer Research UK (CRUK)

## With a vision to cure all cancers, Cancer Research UK is a major cancer research funder with diverse funding

 schemes, extensive patient engagement opportunities and robust infrastructure for knowledge-sharing activities.
## Innovative Research Funding

CRUK funds across the research continuum, through select innovative awards:

- Multidisciplinary Funding: Supports collaborations between cancer researchers and scientists from engineering/physics (e.g. Multidisciplinary Project Award).
- Pediatric/AYA Funding: Enables innovative collaborations in childhood cancer research. (e.g. SU2C-CRUK Pediatric Cancer New Discoveries Challenge, Children and Young People's Cancer Innovation Award).
- Funding for Therapeutics: Aimed at researchers who propose multifaceted programs of several projects running in parallel with an overarching therapeutic aim (e.g. Therapeutic Discovery Pilot/Discovery Awards)


## Patient Engagement

CRUK provides opportunities for patient support and access to researchers through:

- Grand Challenge: Patients and caregivers are involved in identifying pressing issues at two 'Big Think' events, which generated over 400 research ideas across 19 categories. Scientists, patients and caregivers decided on awarding funding $\$ 25 \mathrm{M}$ over 5 years to 4 major research projects.
- Your Involvement Network: Volunteers share their experiences of diagnosis, treatment and care through a range of involvement opportunities that helps CRUK to align its research direction to better meet the needs of people.
- Patient Involvement Toolkit: Comprehensive guidelines for researchers to work with patients in research participation, engagement, involvement.


## Knowledge Translation

CRUK engages partners to facilitate and expedite the translation of discoveries:

- Commercial Partnerships Team: Develops and commercializes new discoveries in research (e.g. therapeutics, vaccines, diagnostics) by leveraging £20 million in industry funding to advance promising cancer research through major partnerships (e.g. AstraZeneca, Merck).
- Entrepreneurial Programs: Connects earlycareer researchers to business accelerators, hosts innovation competitions and bring together researchers and others at innovation summits.
- VC Partnerships: Collaboration with SV Health Investors, a life sciences VC and growth equity firm focused on translating CRUK research.


## Multiple Myeloma Research Foundation (MMRF)

Taking a "disciplined approach to disruption", MMRF accelerates discoveries and clinical trials for multiple myeloma through venture philanthropy, patient-driven data repositories and large-scale collaborations.

## Venture Philanthropy

$$
\begin{aligned}
& \text { MYELOMA } \\
& \text { INVESTMENT FUND }
\end{aligned}
$$

capital for cures

- With an aim to disrupt and de-risk immunooncology, the Myeloma Investment Fund $®$ is a self-sustaining independent venture fund that allows philanthropists (min \$100K donation) to invest in promising companies, clinical assets, and technologies in multiple myeloma.
- In addition to financial support, prospective companies receive access to MMRF's network of pharma companies, academic medical centers, a clinical network of 24 sites (the MMRC), and the largest genomics dataset of any cancer.


## Data-Driven Research and Resources

## MM <br> CureCloud

- Leveraging MMRF's large genomics dataset of $>1,000$ patients worldwide, this dataset is a bold initiative that integrates vast amounts of health data from multiple myeloma patients in the first at-home genomic testing program and provides patients and physicians access to evidencebased personalized insights based on their genomic report.
- Cure Cloud encourages patients to contribute their data to a centralized data hub of longitudinal genomic, immune, and clinical patient data made available to researchers.

Large-Scale Collaborations


- Overseen by MMRF's Chief Medical Officer, the Multiple Myeloma Research Consortium (MMRC) brings together 24 top cancer centers around the world and has conducted nearly 100 Phase I and II trials, which has enrolled thousands of patients to date.
- MMRC has become a center of excellence for multiple myeloma, and is recognized for its streamlined communications, quality trial conduct and a patient-driven research model that has led to faster trial starts and enrollment.


## Alex's Lemonade Stand Foundation (ALSF)

## ALSF has supported leading pediatric oncology research in US and Canada through prioritized funding initiatives across the research continuum, innovative community-driven funding mechanisms and knowledge sharing.

## Focused Grant Competitions

The ALSF Grant Program is strategically designed to fill funding gaps in 3 core areas:

- Early Career Research Grants (e.g. early career investigators, specifically studying RUNX1 leukemia).
- Accelerator Grants (e.g. Centers of Excellence, infrastructure, and research grants focused on advancing research to early phase clinical trials; epidemiology grants on early detection and prevention; data grants on single-cell profiling).
- Quality of Life and Care Grants (e.g. nursing and psychosocial research grants for early career and established researchers).


## Innovative Funding Mechanisms

Working together with its community, ALSF creates innovative and high impact funding opportunities including the:

- Co-Funding Program: ALSF has collaborated with $>25$ community organizations (with min. $\$ 25 \mathrm{~K}$ to invest) to support projects vetted by the scientific advisory board and jointly established funding criteria.
- Crazy 8 Initiative: Bringing together $>90$ top scientists from around the world, ALSF established roadmaps to tackle 8 specific, hard-to-treat cancers/unmet needs through multidisciplinary collaborations that guide ALSF's $\$ 25 \mathrm{M}$ research fund ( $\$ 1-5 \mathrm{M}$ per team) in the C8l initiative over the coming years.


## Knowledge Sharing Initiatives

ALSF provides opportunities for researchers to connect and share knowledge with fellow researchers and the broader cancer community:

- Young Investigator Summit: Sponsored by ALSF's partners (e.g. financial sector), young investigators meet annually with other award grantees and experienced scholars from the funded Centres of Excellence to stimulate collaborations and sharing of knowledge.
- Virtual Childhood Cancer Lecture Series: ALSF organizes free educational webinars led by experts to share their latest research and answer questions from the audience which includes scientists, physicians and advocates.


## Key Takeaways

- Many benchmarks strategically design a mixed funding portfolio. Portfolios are structured to include open competitions across the research continuum while dedicating a significant amount of funding to areas of unmet need (e.g. specific cancer type, research type, research tools and infrastructure). CCS can create a balanced portfolio that supports the breadth of cancer research through open calls focused on discovery/innovative research and targeted funding opportunities in areas of high unmet need, co-funded grants with other funders where priorities align and potentially supplementary funding for researchers that show promising interim results at reporting milestones.
- A diverse community is engaged in setting research priorities. Benchmarks commonly consult a diverse group of stakeholders including researchers, global experts, business strategists, healthcare practitioners and, most importantly, patients/advocates to identify research priorities. CCS should consider engaging its broader community to set the research agenda and ensure that its focus is attuned to the needs of the community, trends in the cancer care environment and the areas where CCS can achieve the greatest impact through research.


## Key Takeaways

- Benchmarks aim to foster a connected research ecosystem. Many benchmarks leverage their networks to create national and global research collaborations that enable multidirectional learning from all stakeholder groups and streamlining efforts to tackle critical challenges. Similarly, CCS is well-positioned to unite stakeholders under a common goal, establish national collaborations and facilitate mechanisms for knowledge sharing and communication of research impact to the broader community.
- Benchmarks have recognized their role in the development of patient data-driven research tools. Many benchmarks provide support to the research community beyond direct research funding by spearheading data-driven research initiatives (e.g. MMRF Cure Cloud, Fox Insight, Fox Trial Finder) for the benefit of patients and care providers but also as essential tools for researchers. Leveraging internal assets and CCS' data strategy (currently under development), CCS can consider spearheading the creation of data platforms and resources that engage the community in research but can also be a source of information for all of the community. HEALTH


## Preliminary Considerations for CCS' Research Strategy

## Preliminary Considerations

Based on the insights gathered through the surveys, consultations and benchmarking, CCS' renewed research strategy must place people (and not researchers) at its core.

## What is driving this rationale?

- CCS' purpose is to unite and inspire all Canadians to take control of cancer.
- As a national organization that provides cancer support programs and services to the entire cancer community and benefits from high public awareness, CCS has a direct connection with people and significant reach across Canada-more so than other cancer funding organizations.
- The future of health research and healthcare (e.g. precision medicines and more personalized preventative solutions) will increasingly require the activation (per the Research Vision), engagement, education and participation of the public and patients.
- The CCS community-including donors, volunteers, patients (as well as researchers)-are expecting to play a greater role in CCS' research activities and want to be better informed on the direction and impact of CCS-funded research.
- It capitalizes on CCS' excellence in scientific review and research investments (e.g. clinical


## Strategic Intent

By building around the cancer community that it serves (all people who are impacted by cancer), CCS can set a bold direction forward through an intent to connect people living in Canada with cancer research activities it supports in order to defeat cancer. trial investments) and needs, and incorporates research more closely with the broader mission.

## Preliminary Considerations, Continued

## In order to connect all people living in Canada to cancer research, CCS requires a research strategy that:

- Engages all people living in Canada-With its national presence, CCS is in the best position to "Activate Populations" so that every person in Canada feels part of and is integral to shaping the cancer research enterprise. Patient-oriented research and personalized healthcare will also only be possible with heightened participation of (all) people.
- Leaves no one behind-CCS is credited for funding the breadth of cancer research and since its mandate includes all people, it will be important for CCS to maintain a certain degree of breadth across all cancer types and the cancer care continuum (but also across regions and populations). However, to ensure that 'no one is left behind', CCS should deprioritize cancer research areas that are well-funded and focus on those that aren't.
- Builds authentic partnerships-People should see themselves as a partner in research and be engaged throughout the research process to allow bidirectional learning to take place between patients, healthcare providers and researchers and establish a learning health system. Building on this spirit of partnership, CCS should also seek to collaborate with diverse partners beyond research organizations (e.g. industry, finance, tech, media) to grow its reach and funding envelope.


## Preliminary Considerations, Continued

- Makes meaningful impact-To close the perceived divide between researchers (particularly biomedical researchers) and CCS' audience (including patients, communities, volunteers and donors), the purpose and expected impact of the research that CCS funds and its importance to patients needs to be clear (even if remote). Given the limited funding envelope, the funding portfolio at CCS will need to be recalibrated to accommodate areas of greatest unmet need/gaps, underserved populations and greatest potential for near-term impact without disregarding the need for basic biomedical discoveries.
- Brings innovations to people-Given that people impacted by cancer recognize CCS as trustworthy and credible, the organization is in a position to fund and promote clinical trials to bring innovative preventive and therapeutic interventions to people. This level of trust can also help to instill the importance of industry in the R\&D process and the private sector's critical role in achieving research impact.
- Embeds research within all CCS programs-Research needs to be brought to the forefront of CCS and be integrated across all programs within the organization. In this way, the research program can harness the experience and knowledge of other programs and given their direct connection to the cancer community and its needs, help to shape the research agenda, share research outcomes, drive fundraising goals, and inform communication and advocacy efforts.


## Appendix

## List of Stakeholders Interviewed

| Name | Stakeholder Type | Title/Affiliation |
| :--- | :--- | :--- |
| Angela Brooks-Wilson | ACOR Member | Distinguished Scientist, Canada's Michael Smith Genome Sciences Centre |
| Michael Cox | ACOR Member | Associate Professor, Department of Urologic Sciences, UBC |
| Peter Siegel | ACOR Member | Scientific Director, IRIC |
| Marc Therrien | ACOR Member | Associate Professor, Departments of Medicine and Radiology, McMaster University |
| Katherine Zukotynski | ACOR Member | Professor, University of Toronto Dalla Lana School of Public Health |
| Paul Demers | ACOR Member | Scientist, Sunnybrook Research Institute |
| Craig Earle | Senior Scientist, Princess Margaret Cancer Centre |  |
| Jennifer Jones | ACOR Member | Adjunct Scientist, Princess Margaret Cancer Centre |
| Michael Moran | ACOR Member | Scientific Director, Cancer Epidemiology and Prevention Research, Cancer Care Alberta |
| Christine Freidenreich | ACOR Member | Director of Research, Saskatchewan Cancer Agency |
| Deborah Anderson | ACOR Member | Professor, Departments of Pathology and Laboratory Medicine and Obstetrics and Gynaecology, UBC |
| David Huntsman | ACOR Member |  |

## List of Stakeholders Interviewed, Continued

| Name | Stakeholder Type | Title/Affiliation |
| :--- | :--- | :--- |
| Tony Reiman | Cancer Researchers (non-ACOR members) | Assistant Dean of Research, Dalhousie Medicine New Brunswick |
| Brad Wouters | Cancer Researchers (non-ACOR members) | Executive Vice-President of Science and Research, University Health Network |
| Hanne Ostergaard | Cancer Researchers (non-ACOR members) | Professor, Department of Medical Microbiology \& Immunology, University of Alberta |
| Nicole Culos-Reed | Cancer Researchers (non-ACOR members) | Professor, Faculty of Kinesiology, University of Calgary |
| Carmen Loiselle | Cancer Researchers (non-ACOR members) | Program Director, Psychosocial Oncology and Oncology Nursing, McGill University |
| Sara Urowitz | Partner Organizations/Health Funders | Executive Director, Canadian Cancer Research Alliance |
| Cindy Morton | Partner Organizations/Health Funders | CEO, Canadian Partnership Against Cancer |
| William Cance | Partner Organizations/Health Funders | Chief Medical and Scientific Officer, American Cancer Society |
| Sung Poblete | Partner Organizations/Health Funders | CEO, Stand Up To Cancer (SU2C) |
| Steve Robbins | Partner Organizations/Health Funders ${ }^{1}$ | Scientific Director of CIHR Institute of Cancer Research and Professor, Oncology, University of Calgary |
| Rob Bristow | International Leaders | Director, Manchester Cancer Research Centre |
| Jeff Hoch | International Leaders | Professor and Chief, Department of Public Health Sciences, UC Davis |
| lain Frame | International Leaders | CEO, National Cancer Research Institute |
| Paul Villanti | Donor | Executive Director of Programs, Movember |
| Fiona Shulte | Cancer Organizations/Gov't Agencies | President, CAPO |
| Jon Tonita | Cancer Organizations/Gov't Agencies | President and CEO, Saskatchewan Cancer Agency |
| Kevin Wilson | Cancer Organizations/Gov't Agencies | Vice President, Population Health, Quality and Research, Saskatchewan Cancer Agency |
| Michael Strong | Cancer Organizations/Gov't Agencies | President, CIHR |

## List of Stakeholders Interviewed, Continued

| Name | Stakeholder Type | Title/Affiliation |
| :--- | :--- | :--- |
| Imogen Coe | EDI Leader | Founding Dean, Faculty of Science, Ryerson University |
| Winston Husbands | EDI Leader | Director of Research, AIDS Committee of Toronto |
| Aisha Lofters | EDI Leader | Chair, Implementation Science, Women's College Hospital |
| Chonnetia Jones | EDI Leader | Vice President, Research, Michael Smith Foundation for Health Research |
| Hermann Nabi | EDI Leader | Assistant Professor, Faculty of Medicine, Université Laval |
| Ruth Ackerman | Patient/Survivor | Director Professional Development, Ontario Pharmacists Association |
| Jill Hamer-Wilson | Patient/Survivor | Lung cancer survivor and advocate; CCS panel member |
| Judy Needham | Patient/Survivor | Chair, Patient Representatives Committee, CCTG |
| Nathalie Baudais | Patient/Survivor | Chair, Metastatic Breast Cancer Advisory Board |
| Don Wood | Patient/Survivor | Principal and Owner, SME Response |
| Heather Douglas | Patient/Survivor | Metastatic breast cancer patient and advocate |
| Etienne Audet-Walsh | Junior Researcher | Assistant Professor, Faculty of Medicine, Université Laval |
| Gillian Hanley | Junior Researcher | Assistant Professor, Department of Obstetrics and Gynecology, Faculty of Medicine, UBC |
| Leia Minaker | Junior Researcher | Assistant Professor, School of Planning, University of Waterloo |
| Miranda Fidler-Benaoudia | Junior Researcher | Adjunct Assistant Professor, Department of Oncology and Community Health Sciences, University of Calgary |

## List of Stakeholders Interviewed, Continued

| Name | Stakeholder Type | Title/Affiliation |
| :--- | :--- | :--- |
| Ronald Barr | Pediatric/AYA Community | Professor Emeritus, McMaster University |
| Sumit Gupta | Pediatric/AYA Community | Staff Oncologist, Hospital for Sick Children |
| Paul Nathan | Pediatric/AYA Community | Pediatric Oncologist, SickKids |
| Jim Whitlock | Pediatric/AYA Community | Division Head, Chair in Hematology/Oncology and Director of Garron Family Cancer Centre, SickKids |
| Patrick Sullivan | Pediatric/AYA Community | Chair of Childhood Cancer Canada, Advocate, Lawyer |
| Kathy Brodeur-Robb | Pediatric/AYA Community | Chair of Childhood Cancer Canada |
| Chantale Hurston | Pediatric/AYA Community | Advocate, Survivor |
| Tina Schomburg | Pediatric/AYA Community | Staff at CCS Lodge, Survivor |
| Antonio Palmer | Pediatric/AYA Community | Co-founder, Advocacy for Canadian Childhood Oncology Research Network (Ac2orn), Parent |
| Christine Mclver | Pediatric/AYA Community | CEO, Kids Cancer Care, Parent |
| Teresa Domingo | Pediatric/AYA Community | CEO of the Kristian Domingo Foundation, Parent, Advocate |
| Len Pace | Pediatric/AYA Community | Fundraiser, Advocate, Parent |

## List of Stakeholders Interviewed, Continued

| Name | Stakeholder Type | Title/Affiliation |
| :--- | :--- | :--- |
| Rob Assimakopoulos | CCS Board | Senior Vice President and Chief Marketing Officer, CIBC |
| Robert Bell | CCS Board | Past President and CEO of UHN and CEO of Princess Margaret Hospital |
| Diane Gosselin | CCS Board | President and CEO, CQDM |
| John Boynton | CES Board | Professor Emeritus, Faculty of Medicine, University of Calgary |
| Chen Fong | CCS Board | COO, Lanterra Developments and President, Lanterra Construction Management |
| Christopher Wein | CCS Board | CEO, CCS |
| Andrea Seale | CCS Executive Leadership Team | Executive Vice President, Finance and Operations, CCS |
| Sara Oates | CCS Executive Leadership Team | Executive Vice President, Brand Marketing, Communications and Digital, CCS |
| Paula Roberts | CCS Executive Leadership Team | Interim Executive Vice President, Community Giving and Leadership Giving, CCS |
| Jane Parsons | CCS Executive Leadership Team | Executive Vice President, Mission, Information and Services, CCS |
| Sandra Krueckl | CCS Executive Leadership Team | Vice-President, Strategic Mission Initiatives and Engagement, CCS |
| Diego Mena | CCS Executive Leadership Team | Vice-President, Cancer Information and Support Services, CCS |
| Laura Burnett | CCS Executive Leadership Team | Vice-President, Cancer Control, CCS |
| Khairun Jivani | CCS Executive Leadership Team | Vice-President, Cancer Prevention, CCS |
| John Atkinson | CCS Executive Leadership Team | Director of Implementation, CCPS, CCS |
| Annemarie Edwards | CCS Executive Leadership Team | Executive Assistant, Mission, Information and Support Services, CCS |
| Kaela Dainard | CCS Executive Leadership Team |  |


[^0]:    ${ }^{1}$ CCS' Advisory Council on Research (ACOR) provides oversight to the CCS peer-review process.
    ARCC: Canadian Center for Applied Research in Cancer Control

