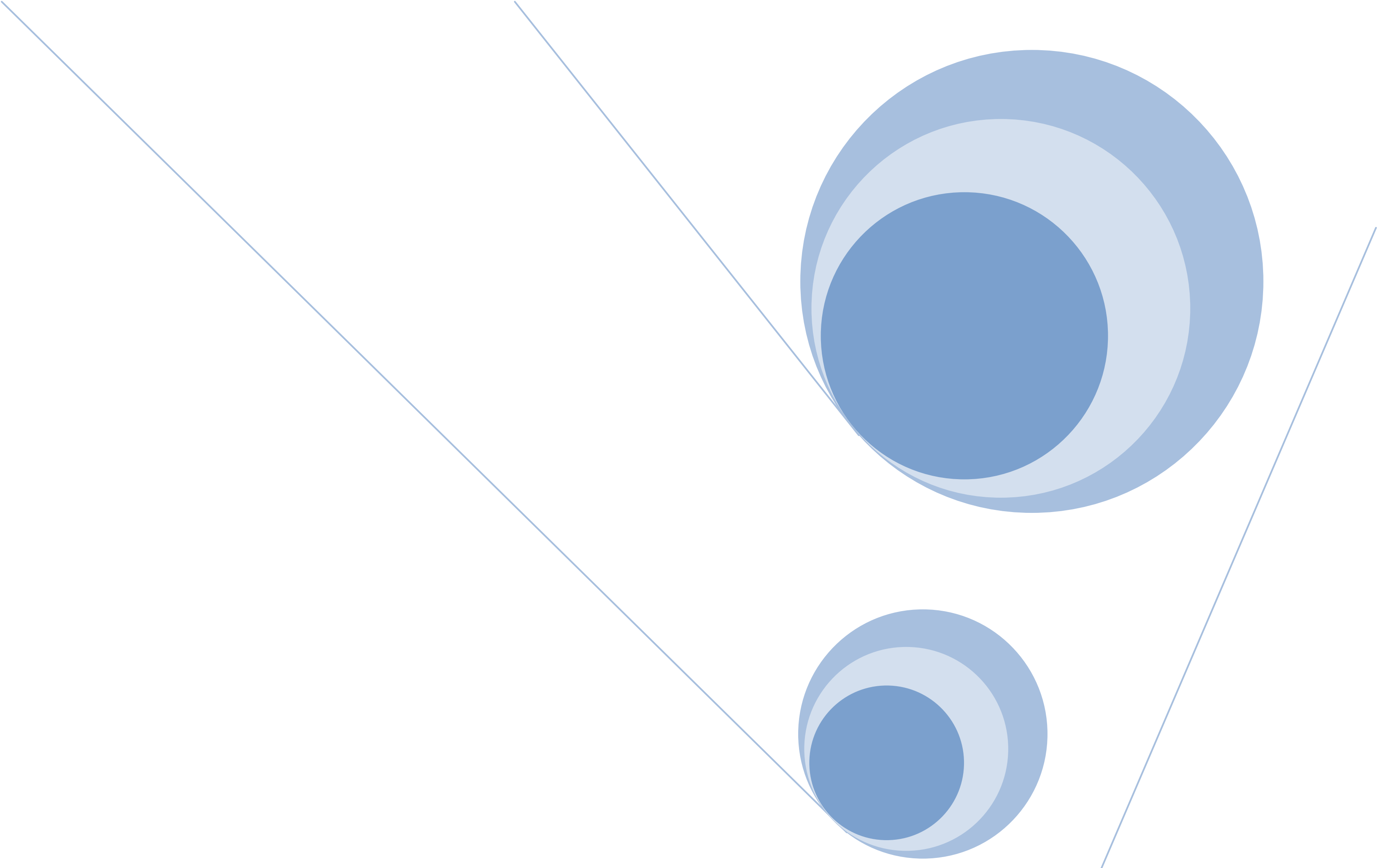
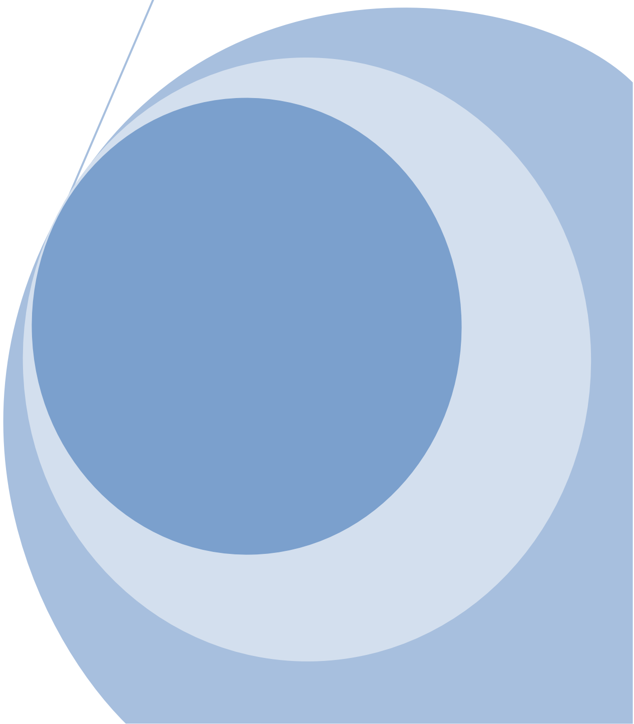


Summary of Results of Two Online Surveys Used to Support the Development of the Pan-Canadian Cancer Research Strategy



SEPTEMBER 2010

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The surveys described in this report were developed by Mr. Matthew Norton, Mr. Robert McKay, and Ms. Maria Milanetti at *n*D Insight with input from the CCRA Strategic Planning Subcommittee as part of the process of data gathering for the pan-Canadian cancer research strategy. We would also like to acknowledge the Canadian Cancer Society for its promotion of the public survey and for providing a link to the public survey on its web portal. The Canadian Cancer Action Network (CCAN) was also instrumental in promoting the public survey.

Our thanks to the following individuals (listed alphabetically) for their advice on earlier drafts of this report: Ms. Fay Bennie (Canadian Partnership Against Cancer), Dr. Elizabeth Eisenhauer (Canadian Cancer Research Alliance/Canadian Partnership Against Cancer), Dr. Jim Hudson (on behalf of the Canadian Breast Cancer Foundation), Ms. Irene Nicoll (Canadian Partnership Against Cancer), and Dr. Naisu Zhu (Canadian Institute for Health Information). This report was prepared by Kim Badovinac and Stuart Edmonds.

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1. INTRODUCTION

1.1 BACKGROUND: THE PAN-CANADIAN CANCER RESEARCH STRATEGY

The *Pan-Canadian Cancer Research Strategy*, released by the Canadian Cancer Research Alliance (CCRA) and the Canadian Partnership Against Cancer in May 2010, represents a landmark—the first time that Canada's cancer research funders have jointly identified priorities for collaborative investment with the commitment to maximize impact on cancer control and accelerate discovery. By working together, funders hope to avoid duplication and clarify opportunities for increased leverage through the complementary allocation of limited funds.

To ensure that this initial national cancer research strategy was well informed by relevant stakeholder insights and concerns, CCRA conducted a comprehensive consultation process over a nine-month period. The goals for this process were to gather and synthesize detailed input from a broad range of stakeholders, learn from the experience of similar alliances of research funders in comparable jurisdictions, and solicit and document expert advice on the future of cancer research.

Over 1,000 participants were engaged in the stakeholder consultation process, which consisted of four main activities:

- five regional consultation sessions attended by scientists, clinicians, patients/survivors, CCRA member representatives, health-care system managers, and policy-makers
- over 30 key informant interviews held with both Canadian and international experts in cancer research and cancer research funding systems
- a targeted online survey of cancer researchers
- an online survey of patients, survivors, and the concerned public

This report describes the results of the two online surveys and is intended as part of the background materials for the research strategy. Opinions surveys conducted by Research Canada and its national partners indicate that health and medical research is a top priority for Canadians, with both basic and clinical research playing important roles.[1]

1.2 WHY SURVEY PATIENTS, SURVIVORS & CONCERNED MEMBERS OF THE PUBLIC?

This survey was an exploratory effort to gather the perceptions and opinions of people affected by cancer—a larger group than could be reached through the regional consultations and other data gathering activities undertaken as part of the strategic planning process. Cancer patients are important constituents for cancer research funders given that cancer research is conducted for the ultimate benefit of patients and the patient voice is a vital one in ensuring that the research agenda is well informed and well rounded.

An online methodology was selected because it was an economical and efficient way to collect data from this group within the time constraints of the larger strategic planning process. Online surveys allow a large amount of data to be collected in a short period of time and they remove the processing/data entry step of data collection. Internet use, as assessed in the 2009 Canadian Internet Use Survey sponsored by Industry Canada, is at the 80% level in Canada. Although there is variability in the rate of Internet use on the basis of community size and income level, these differences appear to be narrowing over time.[2]

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[1] For the latest survey, see *Canada Speaks! 2010: Canadians Go for Gold in Health and Medical Research* (January 2010) at http://www.canadaspeaks2010.ca/.

[2] See "Canadian Internet Use Survey" in *The Daily*, Monday May 10, 2010 at Statistics Canada's web site (http://www.statcan.gc.ca/daily-quotidien/1001510/dq100510a-eng.htm).

1.3 WHY SURVEY CANCER RESEARCHERS?

Within the public domain, there was no available information on the viewpoints of a large sample of cancer researchers in Canada on issues relating to research investment allocation. Researchers' opinions on how best to balance the cancer research investment and structure funding programs to support discovery, and their opinions on how funders should collaborate were the specific items included in the survey. While it is expected that researchers would have a particular interest in articulating views consistent with their own areas of research activity, it is important to acknowledge that they are also the ones most in tune with the state of science and what is needed to support, advance, and expedite its progress.

1.4 ORGANIZATION OF THIS REPORT

The surveys were developed independently for separate information gathering processes. While there are some overlapping themes, the questions were not intended to be the same. In this report, we have integrated the findings of both surveys in an effort to provide a comprehensive perspective on opinions regarding cancer research.

Descriptions of the survey methodologies and target groups are presented in the next chapter. The findings chapter focuses on both surveys in terms of distinct items as well as items where the surveys overlapped. The analyses are descriptive and, where comparative analyses were possible, statistically significant differences are highlighted. The discussion highlights major themes derived from the surveys and how future surveys could be strengthened in order to monitor changes in opinions over time.

2. METHODS

For brevity, the survey of patients, survivors, and concerned members of the public is referred to as the **public survey** for the remainder of the report.

2.1 STUDY PARTICIPANTS

2.1.1 Public Survey

This was an exploratory survey based on a convenience (non-random sample). It was intended to target persons in Canada directly or indirectly affected by cancer.

2.1.2 Researcher Survey

We identified researchers using the CCRA Canadian Cancer Research Survey database, which contains information on cancer research projects and their affiliated personnel funded by 37 organizations/initiatives for three calendar years, 2005 to 2007. We included all principal investigators, co-principal investigators, and trainee supervisors (excluding trainees themselves) working at Canadian institutions who had research projects funded at any time between January 1, 2005 and December 31, 2007. The survey population (number of targeted researchers) was 2,137.

2.2 DEVELOPMENT OF THE QUESTIONNAIRE

The surveys were developed by Mr. Matthew Norton, Mr. Robert McKay, and Ms. Maria Milanetti of *n*D Insight with significant input from the CCRA Strategic Planning Subcommittee as part of their broader consultative work undertaken for the pan-Canadian cancer research strategy. The surveys were designed independently, thus there are a limited range of possible comparisons between the public and researcher surveys.

Questions were designed to complement discussion points used as part of the regional consultations. Specific items relating to research areas were based on the Common Scientific Outline (CSO), a classification system specific to cancer research based on broad categories of scientific interest (http://www.cancerportfolio.org/cso.jsp). The CSO is used by the CCRA and other organizations in the U.K. and U.S. to classify and report on cancer research investment.

2.2.1 Public Survey

The survey consisted of closed- and open-ended questions on opinions of cancer research, specifically:

- allocations of research investment across research areas (eight research areas; continuous variables)
- optimal dispersion of research funding (three choices)
- role of non-scientists in setting research priorities (three choices)
- satisfaction with research progress (four-point rating scale)
- most significant gaps in research activities (open-ended)
- most significant opportunities for Canada to contribute to cancer research internationally (open-ended)

It also contained closed-ended items relating to respondent characteristics (i.e., perspective, province, community size, sex, and age range) and an optional open-ended question for respondents who were volunteers/staff/public to indicate the organization that they represented. Both a preamble and a description of cancer research areas were included within the survey in order to help respondents understand the questionnaire intent. The survey was made available in English and French. A copy of the full survey (English) is provided in Appendix A.

2.2.2 Researcher Survey

The survey consisted of eight multi-pronged items on cancer research investment, specifically:

- allocations of research investment across research areas (six research areas; continuous variables)
- importance of different funding mechanisms (seven-point rating scales)
- optimal balance between open investigator-initiated and strategic competitions (proportion; continuous variable)
- optimal dispersion of research funding (two choices)
- grant size/quantity (two choices)
- support for longer term awards (four-point rating scale)
- importance of input from various stakeholders in setting research priorities (five-point rating scale)
- support for types of collaboration among cancer research funding organizations (dichotomous)

It also contained closed-ended items relating to respondent characteristics (i.e., area(s) of research expertise, years active as an independent cancer research investigator, province, community size, sex, and age range). Survey questions were prefaced with a brief introduction. A copy of the survey is provided in Appendix B.

2.3 SURVEY ADMINISTRATION

2.3.1 Public Survey

A link to the survey (both the English and French versions) was posted to the national web site of the Canadian Cancer Society (www.cancer.ca) for the period May 28, 2009 to October 16, 2009. The Canadian Cancer Society is a major cancer charity in Canada and the largest funder of cancer research among organizations in the charitable sector.[3] The Society's site has close to 3.5 million visits and over 13 million pageviews per year.[4]

The survey was promoted by the Canadian Cancer Action Network (CCAN) to its contact audience. CCAN is a volunteer-driven organization dedicated to ensuring that patient interests remain a key priority on the national cancer agenda. The survey was also promoted by the Canadian Partnership Against Cancer through its communication vehicles and to individual members of the Canadian Cancer Research Alliance. SurveyMonkey™ was used to create, publish, and host the survey.

2.3.2 Researcher Survey

A link to the survey was distributed to researchers in personalized emails during the week of May 11, 2009. Respondents completed the surveys over the period of May 11, 2009 to July 21, 2009. Researchers were sent two email reminders on June 8, 2010 and June 29, 2010. SurveyMonkey™ was used to create, publish, and host the survey.

2.4 DATA ANALYSIS

All analyses and statistical tests were conducted using SAS® Enterprise Guide® 3.0 (SAS Institute Inc., Cary, NC, USA). A *P* value of less than 0.05 was considered statistically significant. Proportions were calculated on the basis of the total number of respondents for each question and expressed as percentage. Depending on the type of variable and number of groups, either Pearson chi-square test, Student *t* test or Kruskal-Wallis one-way ANOVA were used to assess

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[3] Canadian Cancer Research Alliance. (2009). *Cancer Research Investment in Canada, 2007: The Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research in 2007*. Toronto: CCRA.

[4] Email correspondence received June 10, 2010 from Mr. Shital Patel of the Canadian Cancer Society.

differences between groups. For the researcher survey, R-square values for areas of expertise and investment allocations were computed using least-squares linear regression.

2.4.1 Public Survey

One of the categories of the Common Scientific Outline, Cancer Control, Survivorship & Outcomes, was presented in three separate categories: Behaviour & Communication; Health Services; Survivorship & Palliation. This was done to facilitate an understanding of the kinds of research captured within this multi-faceted category.

2.4.2 Researcher Survey

Respondents were asked to indicate their primary area of research interest and expertise from six choices and were permitted to select as many areas as were applicable. This variable was treated as an interval scale such that each area selected was equally weighted and, when summed together, would equal 1 (e.g., if the respondent selected "Biology" and "Treatment", each area was weighted at 0.5).

3. FINDINGS

3.1 RESPONDENTS

3.1.1 Public Survey

There were 326 survey respondents. As expected given that convenience sampling was used, the sample was not found to be representative of the Canadian population in terms of sex,[5] province, community size or age group. Furthermore, the optional question regarding organizational affiliation collected at the end of the survey suggested that respondents from specific organizations may have been overrepresented. Nonetheless, some of the results may yield insights about the opinions of people who have a vested interest in cancer research.

All closed-ended questions were answered by 87.1% of respondents. More female than male respondents had fully completed responses to these questions (91.2% compared to 85.1%, respectively) and respondents completing the English form of the survey were also more likely to have fully completed responses (88.1% of respondents to the English form and 50.0% of respondents to the French form). The item response rates were 71.2% and 58.6%, respectively, for the two stand-alone open-ended items: "What do you see as the most significant gaps in Canada's current cancer research activities?" and "What do you see as the most significant opportunities in the future for Canada to contribute to cancer research internationally?"

Respondents were asked to identify themselves from one of five perspectives:

- cancer patient (currently being treated)
- cancer survivor (received treatment in the past)
- family member of cancer patient or survivor
- volunteer or staff member at a cancer organization
- concerned member of the public

All five perspectives were represented, with the largest group being family members (Figure 3.1.1). It is noteworthy that in the optional, open-ended question regarding organizational affiliation at the end of the survey, a number of respondents elected to elaborate that they represented more than one perspective.

Respondent characteristics are summarized in Table 3.1.1. In this table and for the remainder of the findings for the public survey, we have grouped cancer patients, survivors and family members into one group (i.e., those personally affected by cancer) and the remaining two groups into a second group (i.e., those indirectly affected by cancer). Although we recognize that responses by province would be of interest to funding organizations, the sample size was too small to provide reliable comparisons.

The two groups were similarly distributed in terms of sex and age group. Four of every five respondents were between the ages of 35 and 69. The majority (72.1%) were from communities with 100,000 or more people. There were proportionately more volunteers/staff/public respondents from communities of 1.5M people or more. In terms of province, the largest proportion of respondents was from Ontario. There were proportionately more

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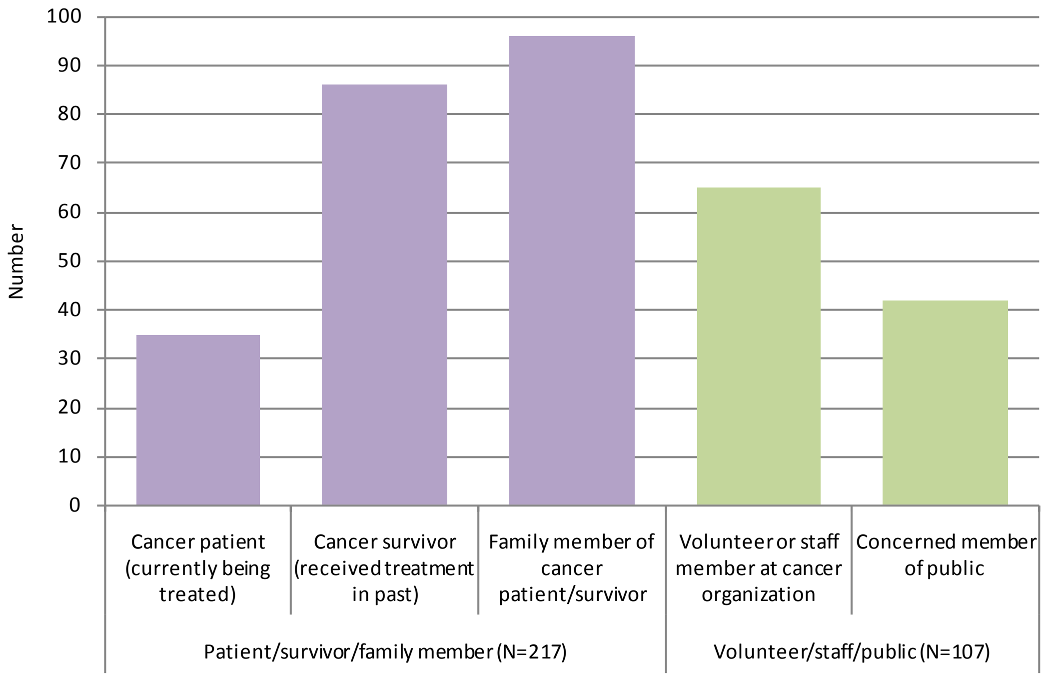
[5] Respondents were predominately female and there is some support that this would be expected. For example, there is evidence to suggest that women are more likely than men to use the Internet for information about health and medical conditions (see Weaver, J.B. et al. (2009). Profiling characteristics of Internet medical information users. *Journal of the American Medical Informatics Association*, 16(5):714-22). In addition, the distribution of women working in the non-profit health sector at three women to every man is also another likely contributor to the imbalance in the sex distribution of survey respondents (see McMullen, K. & Schellenberg, G. (2002). *Mapping the Non-Profit Sector.* CPRN Research Series on Human Resources in the Non-profit Sector, No. 1. Ottawa: Canadian Policy Research Networks).

patients/survivors/family members than volunteers/staff/public from Nova Scotia and proportionately more volunteers/staff/public from Ontario.

FIGURE 3.1.1

NUMBER OF RESPONDENTS BY PERSPECTIVE - PUBLIC SURVEY



3.1.1 Researcher Survey

A total of 616 of the 2,137 targeted researchers (i.e., those asked to participate in the survey) responded to the survey (response rate of 28.8%). The sex distribution of respondents was fairly similar to the survey population (i.e., 34% of respondents and 30% of the targeted researchers were female). A comparison of the provincial distributions of targeted researchers versus survey respondents is provided in Figure 3.1.2. Province was not identified by 97 respondents. The proportions of survey respondents from British Columbia and Manitoba were dramatically lower than the proportions for targeted researchers. The respondent sample may not be representative of the target population in terms of provincial distribution and thus, the findings are at risk of lower accuracy than might be expected from a representative respondent sample.

TABLE 3.1.1

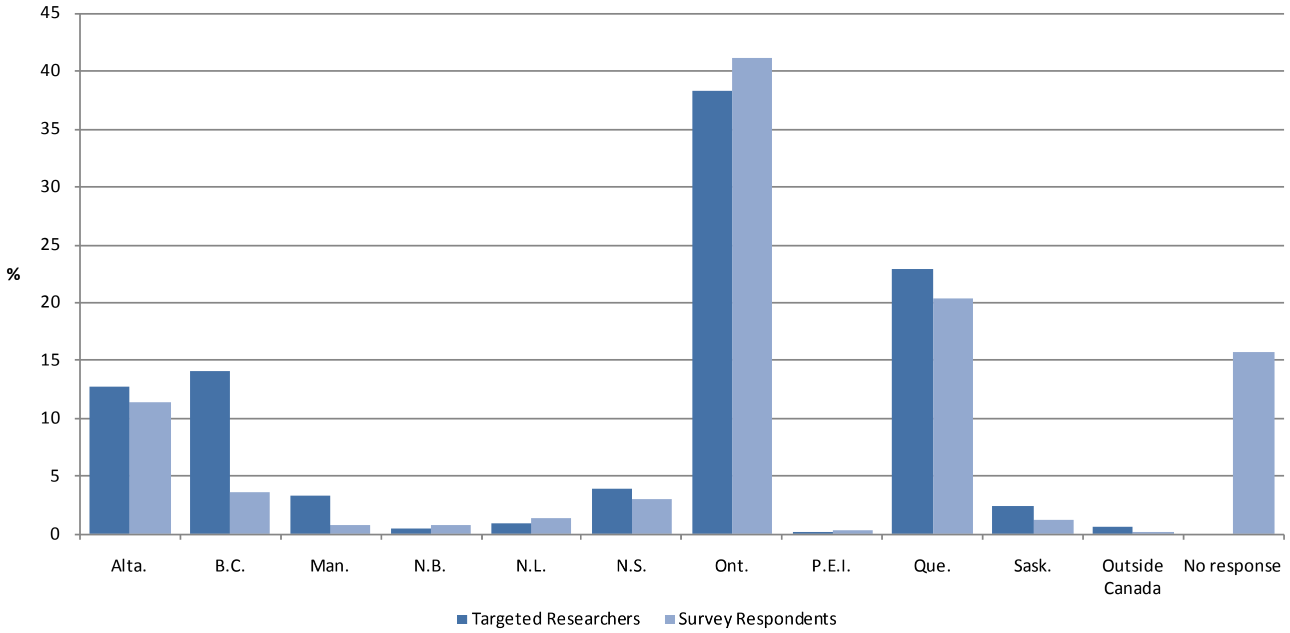
CHARACTERISTICS OF RESPONDENTS TO THE PUBLIC SURVEY

CHARACTERISTIC		TOTAL (N=326) [1]		PATIENT/SURVIVOR/ FAMILY MEMBER (N=217)		VOLUNTEER/STAFF/ PUBLIC (N=107)	
		N	%	N	%	N	%
SEX	Female	217	66.5	144	66.4	73	68.2
	Male	101	31.0	71	32.7	28	26.2
	No response	8	2.5	2	0.9	6	5.6
AGE GROUP	19 and under	1	0.3	1	0.5	0	0.0
	20 to 34	46	14.1	31	14.3	15	14.0
	35 to 49	106	32.5	66	30.4	40	37.4
	50 to 69	155	47.6	109	50.2	44	41.1
	70 and older	12	3.7	9	4.1	3	2.8
	No response	6	1.8	1	0.5	5	4.7
COMMUNITY SIZE	Rural population/low population density	14	4.3	11	5.1	3	2.8
	Population under 10,000	17	5.2	13	6.0	4	3.7
	10,000 to 99,999	53	16.3	37	17.1	16	15.0
	100,000 to 499,999	100	30.7	68	31.3	31	29.0
	500,000 to 1.49M	58	17.8	40	18.4	17	15.9
	1.5M and over	77	23.6	45	20.7	32	29.9
	No response	7	2.1	3	1.4	4	3.7
PROVINCE/ TERRITORY	Alta.	23	7.1	18	8.3	5	4.7
	B.C.	62	19.0	40	18.4	22	20.6
	Man.	3	0.9	3	1.4	0	0.0
	N.B.	6	1.9	4	1.8	2	1.9
	N.L.	12	3.7	6	2.8	6	5.6
	N.S.	62	19.0	48	22.1	13	12.2
	N.U.	0	0.0	0	0.0	0	0.0
	N.W.T.	2	0.6	2	0.9	0	0.0
	Ont.	125	38.3	77	35.5	47	43.9
	P.E.I.	5	1.5	1	0.5	4	3.7
	Que.	14	4.3	11	5.1	3	2.8
	Sask.	11	3.4	7	3.2	4	3.7
	Y.T.	0	0.0	0	0.0	0	0.0
	No response	1	0.3	0	0.0	1	0.9

[1] There were 2 respondents who did not indicate their perspective. These individuals are included in the Total column.

FIGURE 3.1.2

DISTRIBUTION OF TARGETED RESEARCHERS AND RESPONDENTS OF THE RESEARCHER SURVEY BY PROVINCE



Most (70.0%) researchers responded in full to all closed-ended items in the survey. Respondents from the youngest age group (under 34) were more likely than respondents from the older age groupings to have an item non-response of one or more items. The question, "In an era of scarce funding for cancer research, do you believe it is better for the cancer research funding organizations to have more grants available of smaller sizes or fewer, larger grants?" had the highest item non-response among the research-related questions (42 respondents failed to answer this question).

Table 3.1.2 summarizes the respondent characteristics. Two-thirds of the respondents were male. Most respondents (77.8%) had at least six years of experience as an active independent researcher. In terms of age group, over half of respondents fell into the 35-49 year age group. Most respondents were from communities with populations of one million people or more. Two of every five respondents were from Ontario. Just over half of respondents indicate one area of research expertise.

Figure 3.1.3 shows the distribution of respondents by areas of expertise. Biology was the most frequently selected area of research—in fact, one in five respondents identified Biology as their only area of expertise. Statistically significantly more males indicated Biology as an area of expertise when compared with female respondents, while there were significantly more female respondents who indicated Prevention and Cancer Control, Survivorship, Outcomes Research & Health Services as their areas of expertise.

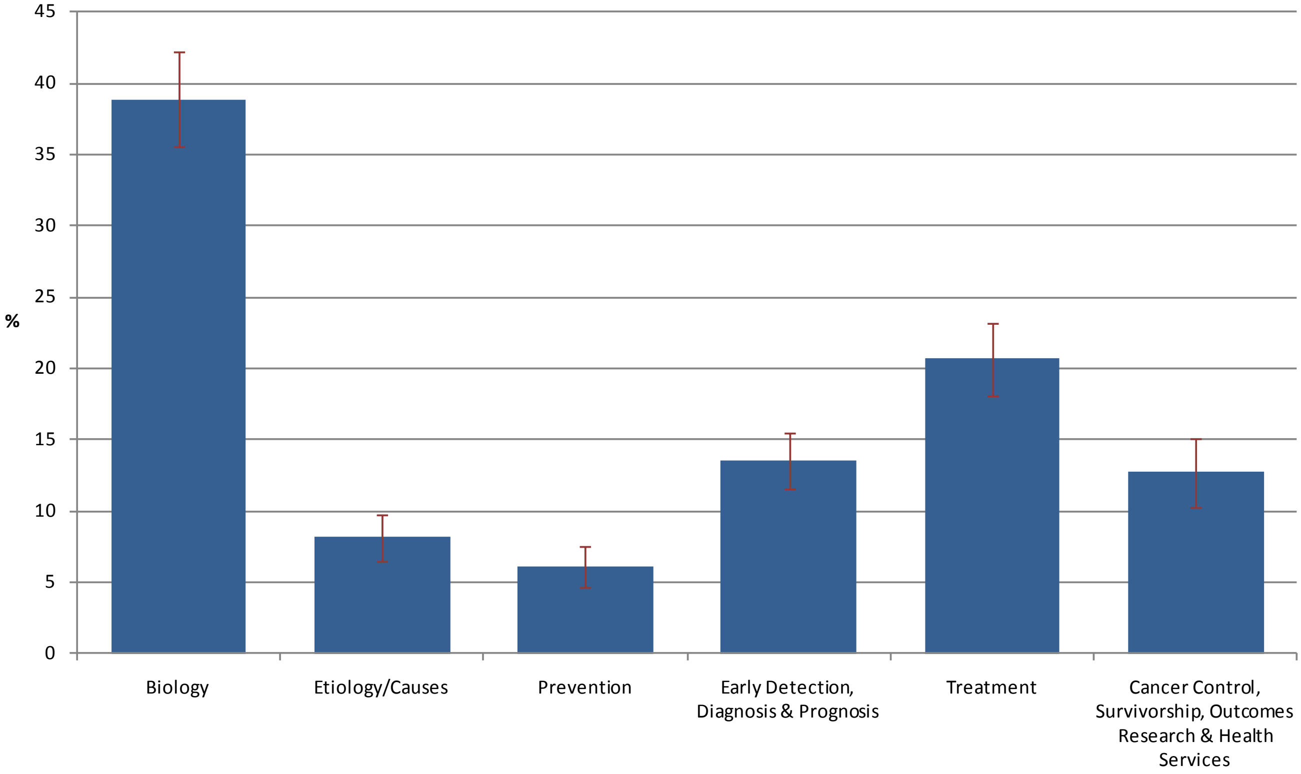
TABLE 3.1.2

CHARACTERISTICS OF RESPONDENTS TO THE RESEARCHER SURVEY

CHARACTERISTIC		TOTAL (N=616)	
		N	%
SEX	Female	203	33.0
	Male	395	64.1
	No response	18	2.9
YEARS OF EXPERIENCE	Less than 3 years	44	7.1
	3 to 5 years	91	14.8
	6 to 10 years	162	26.3
	11 to 20 years	197	32.0
	21+ years	114	18.5
	No response	8	1.3
AGE GROUP	Under 34	9	1.5
	35 to 49	320	52.0
	50 to 69	266	43.2
	70 and older	4	0.6
	No response	17	2.7
COMMUNITY SIZE	Under 500,000	138	22.4
	500,000 to 999,999	114	18.5
	1M and over	339	55.0
	No response	25	4.1
PROVINCE	Alta.	70	11.4
	B.C.	22	3.6
	Man.	5	0.8
	N.B.	5	0.8
	N.L.	9	1.4
	N.S.	19	3.1
	Ont.	253	41.1
	P.E.I.	2	0.3
	Que.	125	20.3
	Sask.	8	1.3
	Outside Canada	1	0.2
	No response	97	15.7
NUMBER OF AREAS OF EXPERTISE	One area	326	52.9
	Two areas	161	26.1
	Three areas	85	13.8
	Four areas	26	4.2
	Five areas	7	1.1
	Six areas	2	0.3
	No response	9	1.5

FIGURE 3.1.3

DISTRIBUTION OF AREAS OF EXPERTISE - RESEARCHER SURVEY (WITH 95% CONFIDENCE INTERVALS)



3.2 INVESTMENT ALLOCATIONS ACROSS RESEARCH AREAS

3.2.1 Public Survey

Respondents to the public survey were asked to allocate an investment of $100 across eight different areas of cancer research. The areas were defined for respondents and were based on the major categories of the Common Scientific Outcome, an internationally used classification system applied to cancer research. As previously mentioned, the sixth category of the Common Scientific Outline was divided into three distinct areas for the purposes of the public survey.

Looking at overall responses, the three categories, Prevention, Early Detection, Diagnosis & Prognosis, and Treatment, were each allocated around $16. There were no differences in mean allocations given to the eight research areas between the two groups (Figure 3.2.1). Of note, respondents who allocated more money to Treatment were less likely to allocate money to Etiology/Causes and Prevention (and vice versa). Volunteers/staff/public, who were male, allocated on average $9 more to Prevention than the other groups, a statistically significant finding. Males, regardless of group, made higher allocations than females to Survivorship & Palliation research.

An earlier U.K. study, which employed a consultative, participatory action approach to gathering research priorities from cancer patients[6] identified the top three research priorities as: (1) impact on life, how to live with cancer, and

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[6] Macmillan Cancer Support report, "The research priorities of people affected by cancer," part of The Macmillan Listening Study. Published by the Macmillan Research Unit at the University of Southampton in August 2006.

related support issues; (2) risk factors and causes; and (3) early detection and prevention. It is noteworthy that the emphasis on survivorship was not echoed by respondents of our public survey.

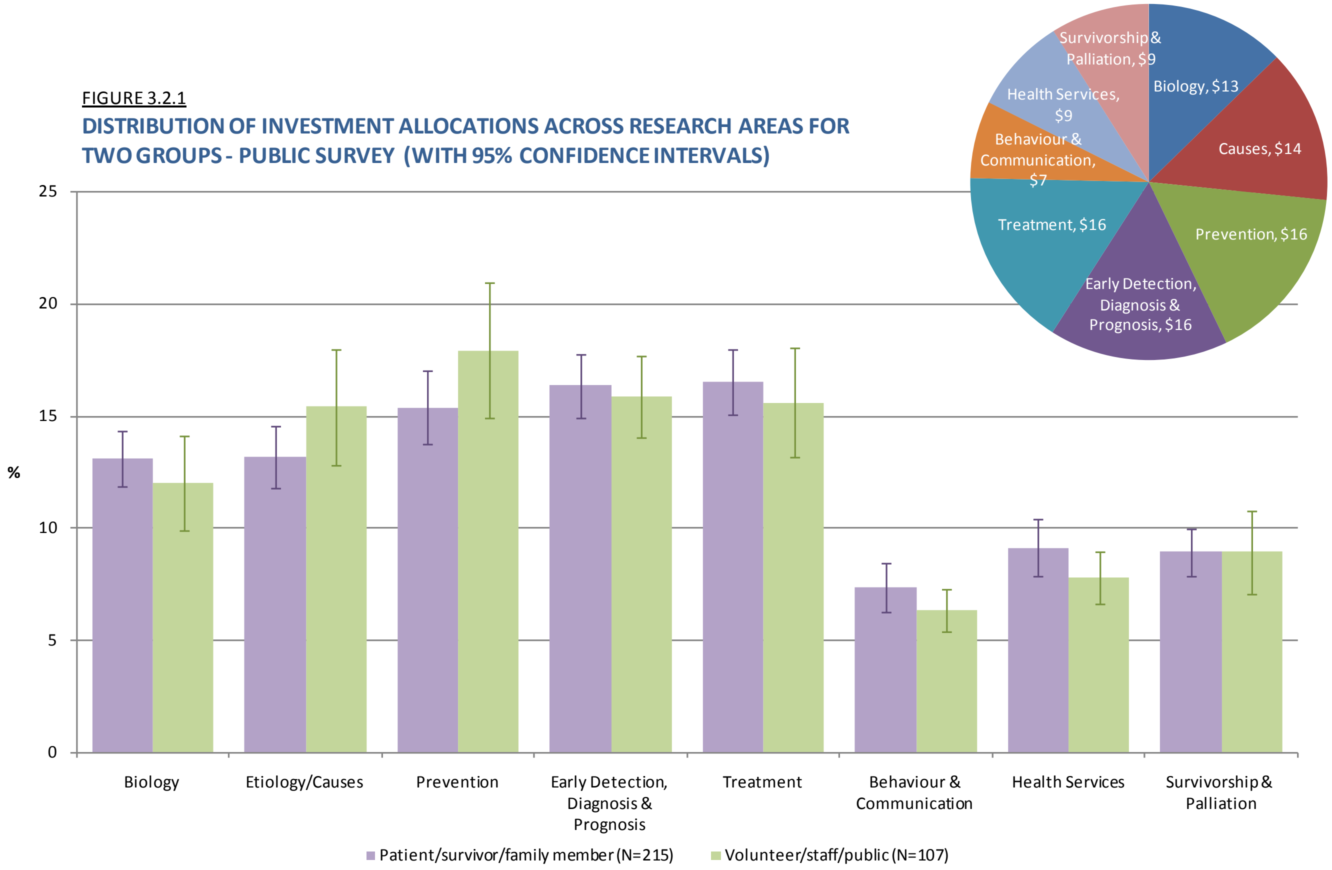


FIGURE 3.2.1

DISTRIBUTION OF INVESTMENT ALLOCATIONS ACROSS RESEARCH AREAS FOR TWO GROUPS - PUBLIC SURVEY (WITH 95% CONFIDENCE INTERVALS)

3.2.2 Researcher Survey

Respondents to the researcher survey were also asked for their opinions on how the investment in cancer research should be allocated across the categories of the Common Scientific Outline. For the researchers, the original six categories of the classification were used.

Looking at overall responses, Biology received one-quarter of the allocation while on the low end, Etiology/Causes and Cancer Control, Survivorship, Outcomes Research & Health Services were each allocated an average of 12% (Figure 3.2.2). The allocations given by female and male respondents were statistically significantly different for the areas of Biology, Prevention, and Cancer Control, Survivorship, Outcomes Research & Health Services. This is largely due to the fact that area of expertise was a strong predictor of investment—namely, researchers' allocations of research dollars were aligned with their own area(s) of expertise (Table 3.2.1). Allocations to Biology and Prevention, however, were also linked to respondent sex independent of area of expertise. That is, female respondents who did not indicate Prevention as an area of expertise allocated more, on average, to Prevention than their male counterparts while male respondents who did not indicate Biology as an area of expertise allocated more, on average, to Biology than their female counterparts.

FIGURE 3.2.2

DISTRIBUTION OF RESPONDENTS' INVESTMENT ALLOCATIONS ACROSS CANCER RESEARCH AREAS - RESEARCHER SURVEY (WITH 95% CONFIDENCE INTERVALS)

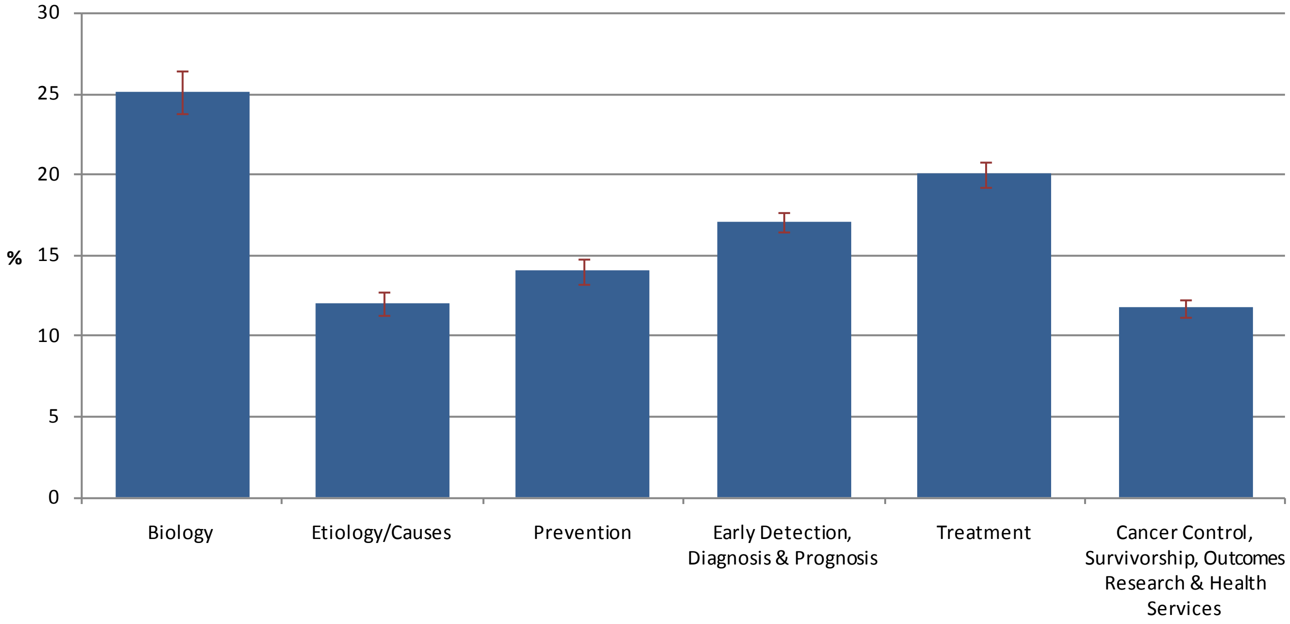


TABLE 3.2.1

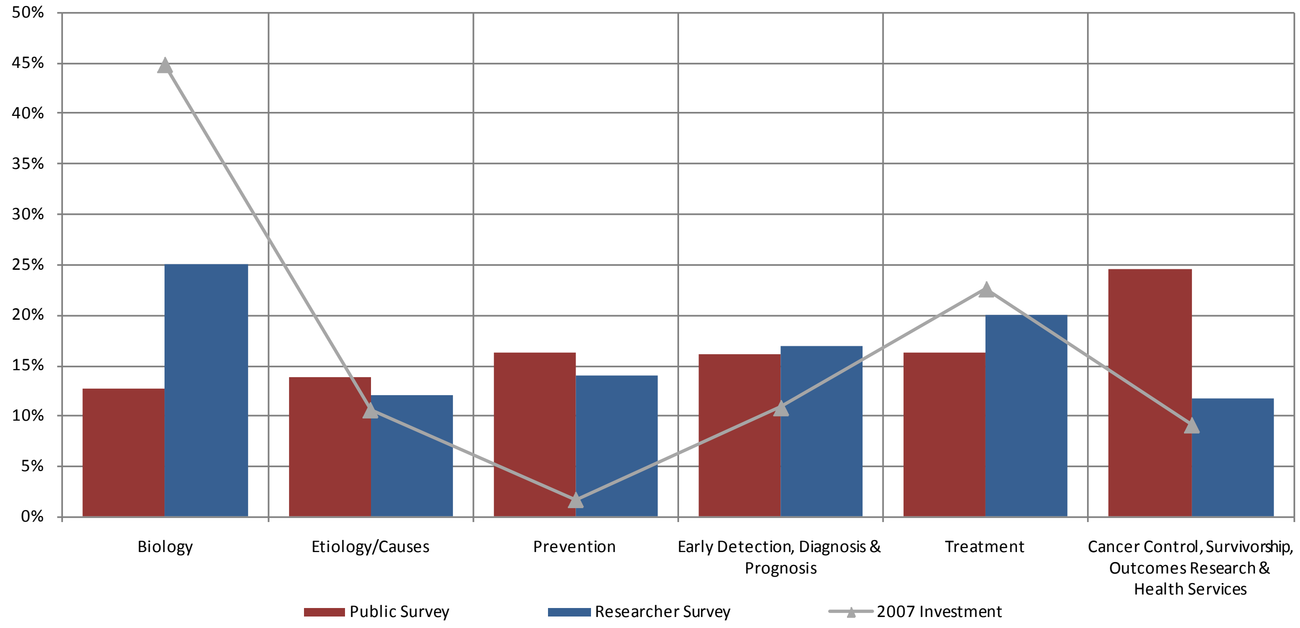
PREDICTION OF INVESTMENT ALLOCATION FROM AREA OF EXPERTISE – RESEARCHER SURVEY (R-SQUARE)

	INVESTMENT ALLOCATION					
AREA OF EXPERTISE	**Biology**	**Etiology/ Causes**	**Prevention**	**Early detection, diagnosis & prognosis**	**Treatment**	**Cancer control, survivorship, outcomes & health services**
Biology	0.35	0.02	0.09	0.02	0.05	0.10
Etiology/Causes	0.03	0.22	0.00	0.00	0.02	0.01
Prevention	0.04	0.00	0.12	0.00	0.01	0.00
Early detection, diagnosis & prognosis	0.02	0.00	0.00	0.10	0.00	0.00
Treatment	0.03	0.02	0.00	0.00	0.17	0.00
Cancer control, survivorship, outcomes & health services	0.09	0.00	0.02	0.00	0.00	0.21

Figure 3.2.3 compares the investment allocations from the public survey and the researcher survey with the actual investment in 2007,[7] which is the latest data available. For the purposes of this graph, responses to the public survey for the three categories, Behaviour & Communication, Health Services, and Survivorship & Palliation, were grouped under Cancer Control, Survivorship, Outcomes Research & Health Services and this may have resulted in higher values for this category than if respondents had been provided with a single category choice.

FIGURE 3.2.3

DISTRIBUTION OF INVESTMENT ALLOCATIONS BY SURVEY RESPONDENTS AND ACTUAL INVESTMENT IN 2007



The data reveal statistically significant differences in terms of opinions of researchers and the public in allocations for Biology and Cancer Control, Survivorship, Outcomes Research & Health Services (although the latter may be an artifact of the differences in the item for the public and researcher surveys). There were also areas of convergence, namely for Early Detection, Diagnosis & Prognosis, Etiology/Causes, and Prevention, and to a lesser extent, Treatment.

The proportions of the actual investment for 2007 were statistically significantly different for both the public and researcher surveys in the areas of Biology, Prevention, Early Detection, Diagnosis & Prognosis, and Cancer Control, Survivorship, Outcomes Research & Health Services. It is noteworthy that the importance of prevention research has already been recognized by the cancer research funding community and recent initiatives have been launched to address this gap.[8] The allocation for Treatment given by respondents of the public survey was also found to be significantly lower than the actual investment proportion, but it was not statistically significantly different from the allocation made by respondents of the researcher survey. Only in the area of Etiology/Causes were all three proportions similar.

In the event that future surveys are conducted, this comparison would be valuable to repeat to assess changes in opinions and actual investment patterns.

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[7] Canadian Cancer Research Alliance. (2009). *Cancer Research Investment in Canada, 2007: The Canadian Cancer Research Alliance's Survey of Government and Voluntary Sector Investment in Cancer Research in 2007*. Toronto: CCRA.

[8] CCRA recently published a report aimed at quantifying the cancer risk and prevention research investment using a novel classification paradigm. It establishes baseline data. This report can be downloaded from http://www.ccra-acrc.ca/PDF%20Files/Prev_2005-07_EN.pdf.

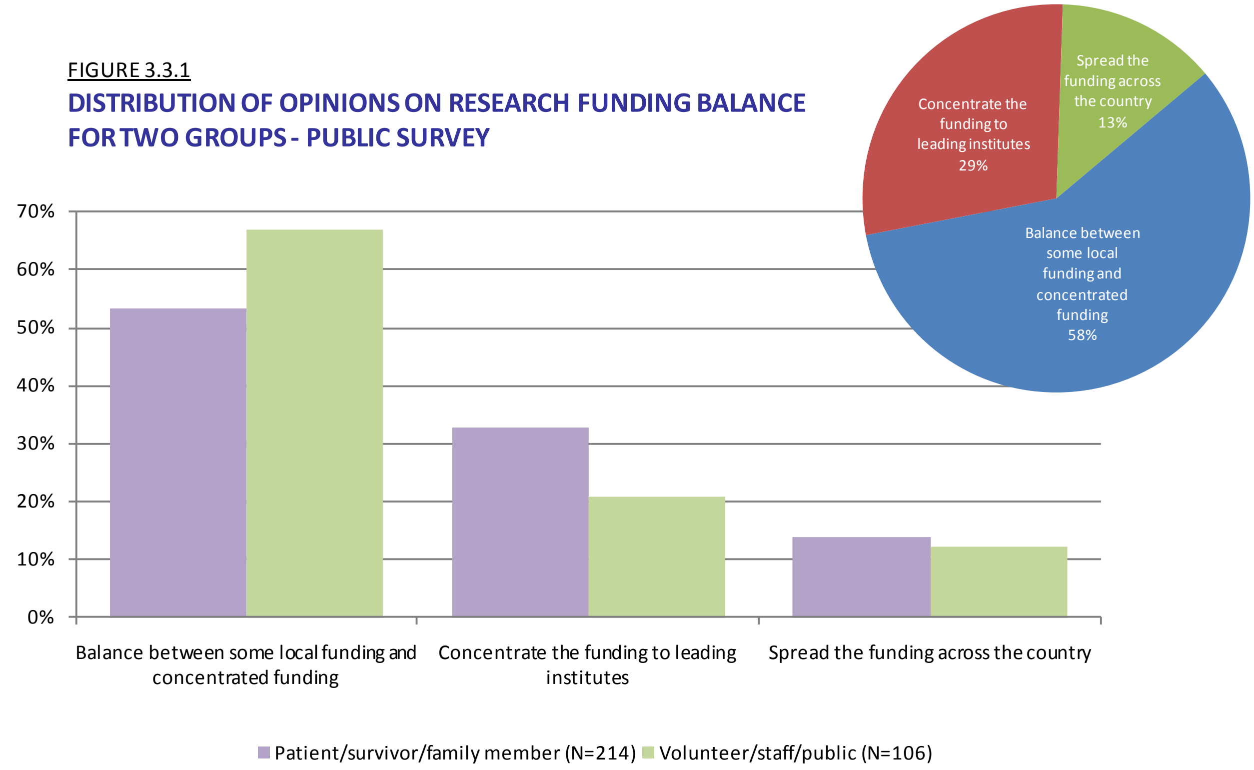
3.3 FUNDING SPREAD

3.3.1 Public Survey

Respondents to the public survey were asked to indicate whether it was important to spread research funding across provinces and institution types, concentrate funding at national centres of excellence, or provide a balanced mix. Most respondents (58.1%) took the middle ground, indicating that a balance between some local funding and concentrated funding was preferred (Figure 3.3.1 – pie chart) and the balanced option was supported at a proportionately higher level by the volunteer/staff/public respondents (Figure 3.3.1 – bar chart).

FIGURE 3.3.1

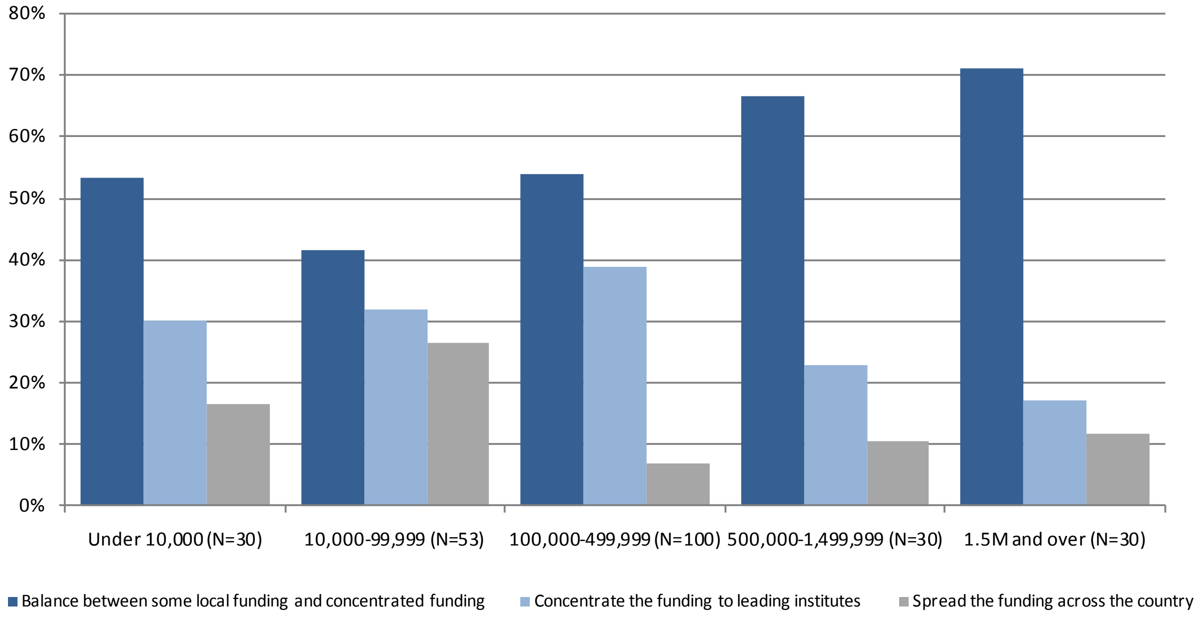
DISTRIBUTION OF OPINIONS ON RESEARCH FUNDING BALANCE FOR TWO GROUPS - PUBLIC SURVEY



In Figure 3.3.2, the distribution of opinions on funding balance by community size of respondents to the public survey is presented. With the exception of respondents in communities under 10,000 people, the proportion of support for a balanced approach increased as community size increased.

FIGURE 3.3.2

DISTRIBUTION OF OPINIONS ON RESEARCH FUNDING BALANCE BY COMMUNITY SIZE - PUBLIC SURVEY



3.3.2 Researcher Survey

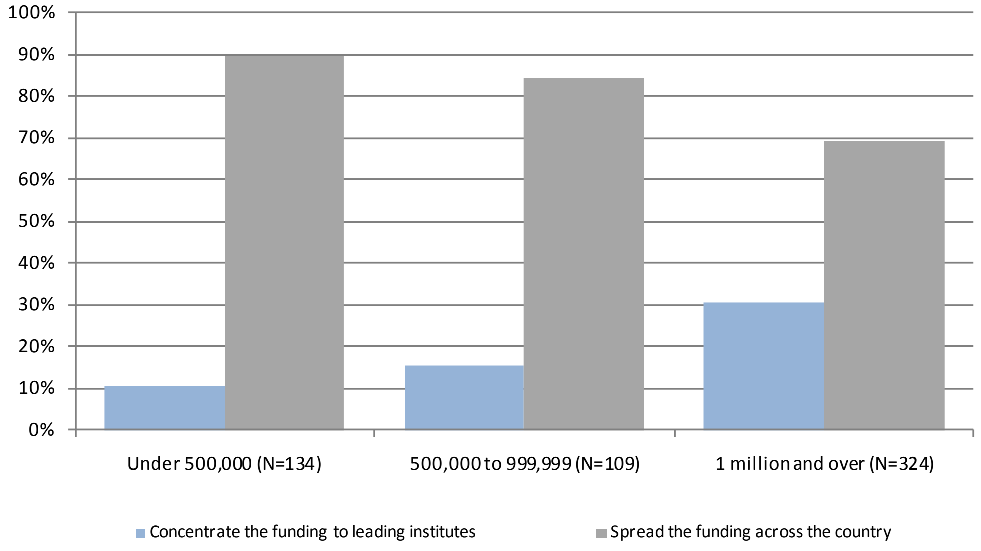
In a similar question, respondents to the researcher survey were asked to indicate whether it was important to spread research funding across provinces and institution types or to concentrate funding at national centres (two choices instead of three).

The majority of researchers (73.7%) preferred spreading research funding across provinces/institutions.

Responses varied by community size (Figure 3.3.3). Respondents from the largest centres (populations of one million or more) were more likely to support concentrating funding at national centres. An analysis of open-ended comments for this item revealed a common theme for the support of research excellence.

FIGURE 3.3.3

DISTRIBUTION OF OPINIONS ON RESEARCH FUNDING BALANCE BY COMMUNITY SIZE - RESEARCHER SURVEY



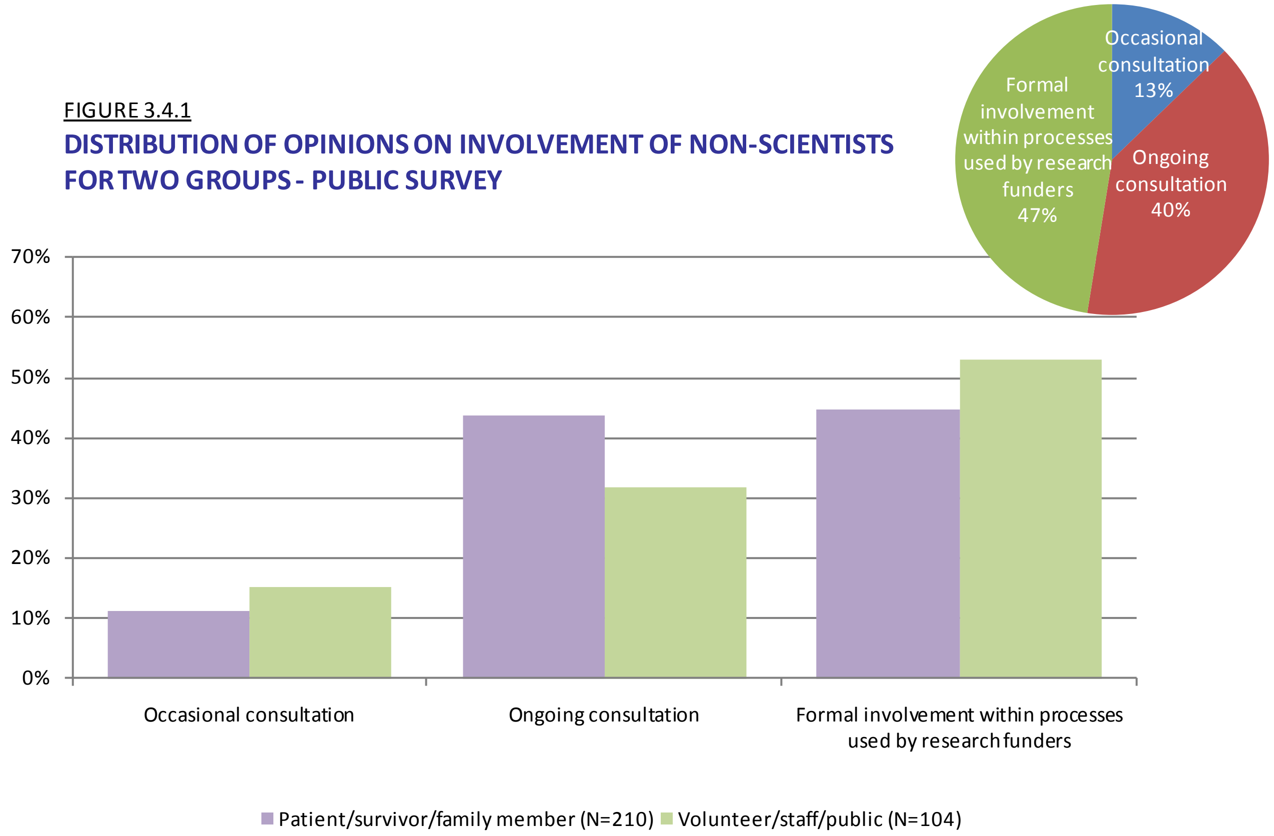
Although this item was not uniformly structured in both surveys, the combined findings show that researchers' support for concentrated funding increased as their community size increased while for the public, there was a tendency to favour a balanced solution in lieu of concentrated funding as community size increased.

3.4 INVOLVEMENT OF NON-SCIENTISTS – PUBLIC SURVEY

Respondents of the public survey were asked to indicate the role that knowledgeable non-scientists should play in setting research priorities. Nearly half of respondents favoured the formal involvement of non-scientists within the processes used by research funding organizations (Figure 3.4.1). Proportionately more patients/survivors/family members supported the ongoing consultation option (43.8% compared to 31.7% of volunteers/staff/public).

FIGURE 3.4.1

DISTRIBUTION OF OPINIONS ON INVOLVEMENT OF NON-SCIENTISTS FOR TWO GROUPS - PUBLIC SURVEY

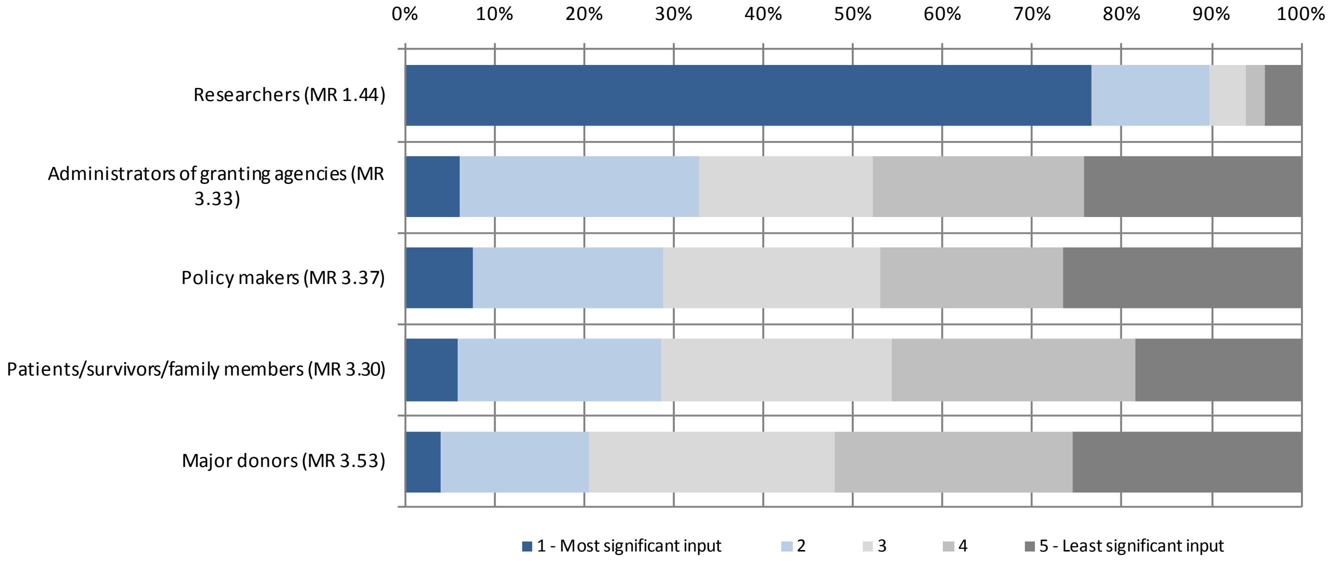


3.5 INPUT INTO PRIORITY SETTING – RESEARCHER SURVEY

Respondents of the researcher survey were asked to rank five stakeholder groups in terms of how significant their input should be in terms of setting Canada's cancer research priorities. Each group was ranked on a five-point scale from 1, most significant input, to 5, least significant input. Researchers clearly indicated that researchers need to have the leading say in setting research strategy—76.7% of respondents ranked researchers as 1-most significant input (Figure 3.5.1). The mean ranking for this stakeholder group was 1.4, which was statistically significantly different from the mean rankings for all other groups.

FIGURE 3.5.1

DISTRIBUTION OF RANKINGS FOR STAKEHOLDERS IN TERMS OF IMPORTANCE OF INPUT INTO SETTING RESEARCH PRIORITIES - RESEARCHER SURVEY



MR = mean ranking

3.6 FUNDING BALANCE AND FUNDING MECHANISMS – RESEARCHER SURVEY

Respondents of the researcher survey were asked to allocate the optimal balance of the research investment in terms of open investigator-initiated versus strategically-based funding competitions. Open investigator-initiated funding competitions are those where the research focus/direction is entirely determined by the researcher. In contrast, strategically-based funding competition stipulate that the research must be conducted within a given area or focus, which is aligned with the strategic priorities of the funding organization. Male respondents were statistically significantly more likely to support open investigator-initiated competitions, with an average allocation of 73.5% compared to 67.6% for females.

Respondents of the researcher survey were also asked to rank the importance of seven types of funding mechanisms on a 7-point scale (1-most important to 7-least important). Operating grants were rated as most important by a wide margin relative to the six other funding mechanisms (Figure 3.6.1). Two of every five respondents rated team grants/program projects with a "1" or "2". Co-sponsored opportunities, where two or more organizations contribute to a funding program, were rated "least important" by 30.8% of respondents.

Figure 3.6.2 shows the mean ratings for the various funding mechanisms by areas of expertise. Although single operating grants were rated as most important regardless of area of expertise, this was especially the case for researchers working in the areas of Biology, Etiology/Causes, and Early Detection, Diagnosis & Prognosis. This graph also shows a distinct pattern of ratings for researchers working in the area of Cancer Control, Survivorship, Outcomes Research & Health Services. These researchers rated career awards and institute support as more important than other respondents. They also had the lowest relative ratings for single operating grants and trainee awards.

FIGURE 3.6.1

DISTRIBUTION OF RESPONDENTS' RATINGS OF IMPORTANCE FOR EACH FUNDING MECHANISM - RESEARCHER SURVEY

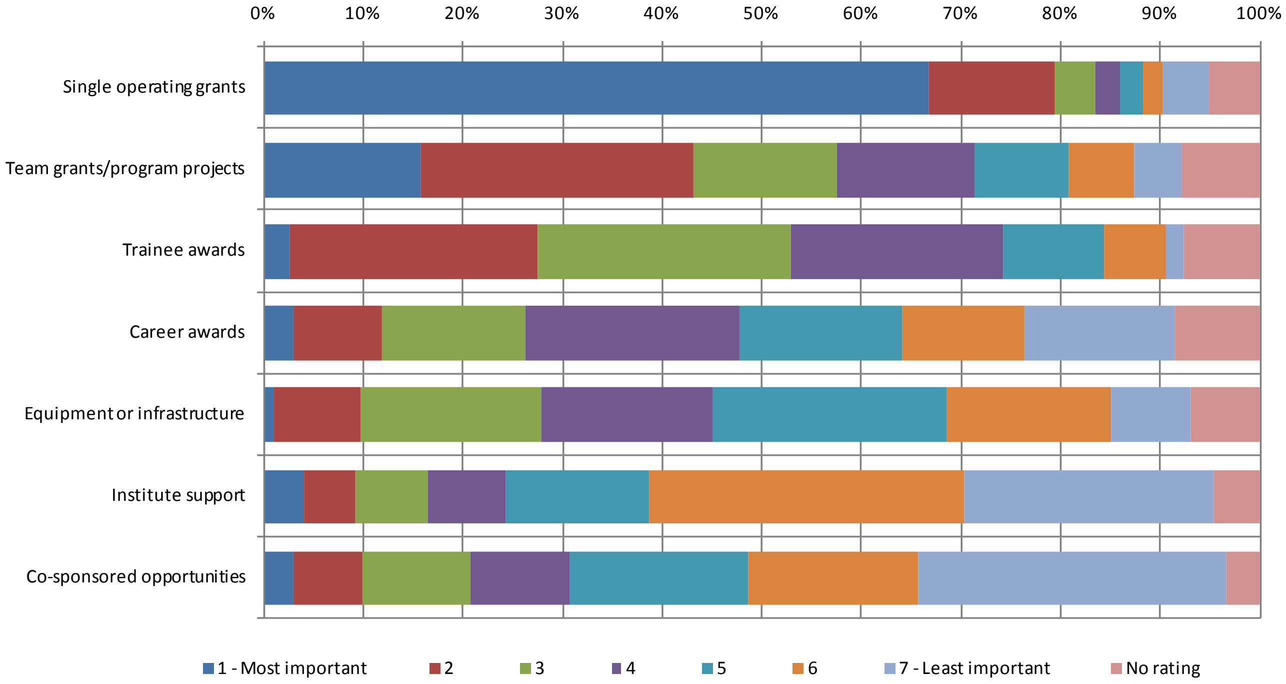
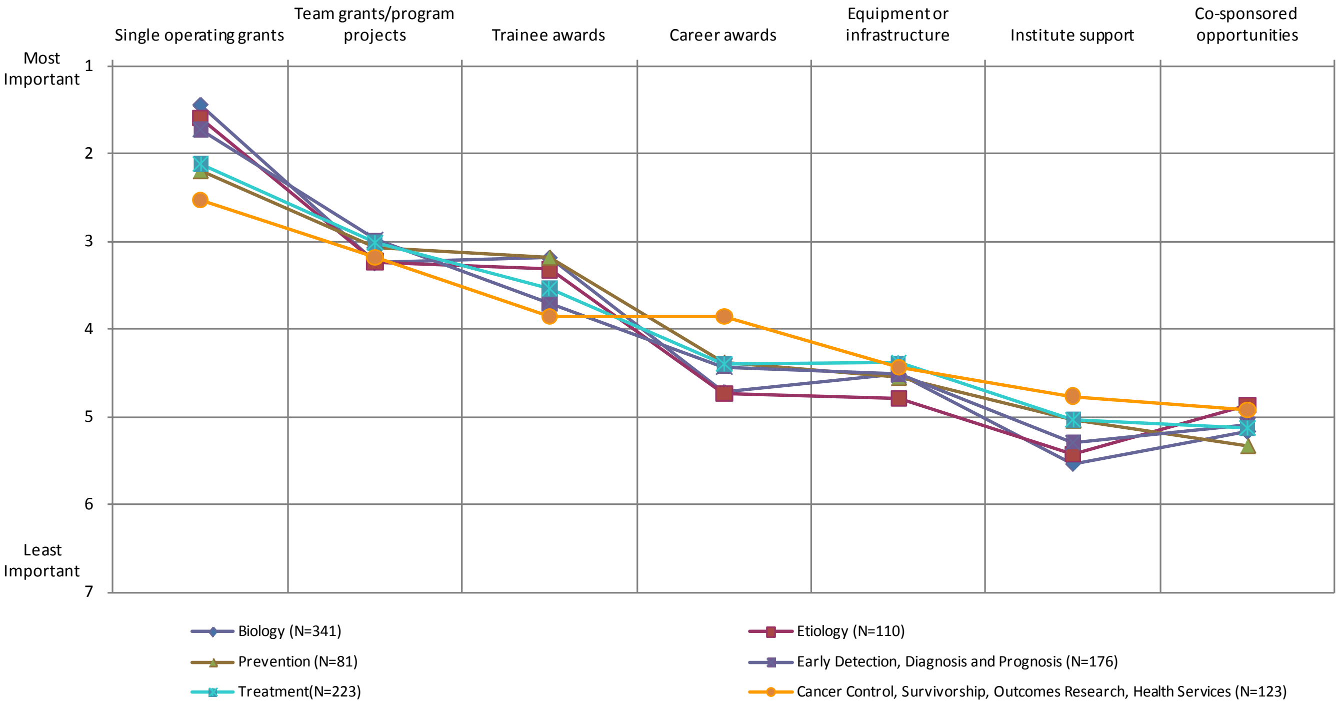


FIGURE 3.6.2

MEAN RATINGS OF IMPORTANCE OF FUNDING MECHANISMS BY RESPONDENTS ACCORDING TO THEIR AREA OF EXPERTISE - RESEARCHER SURVEY

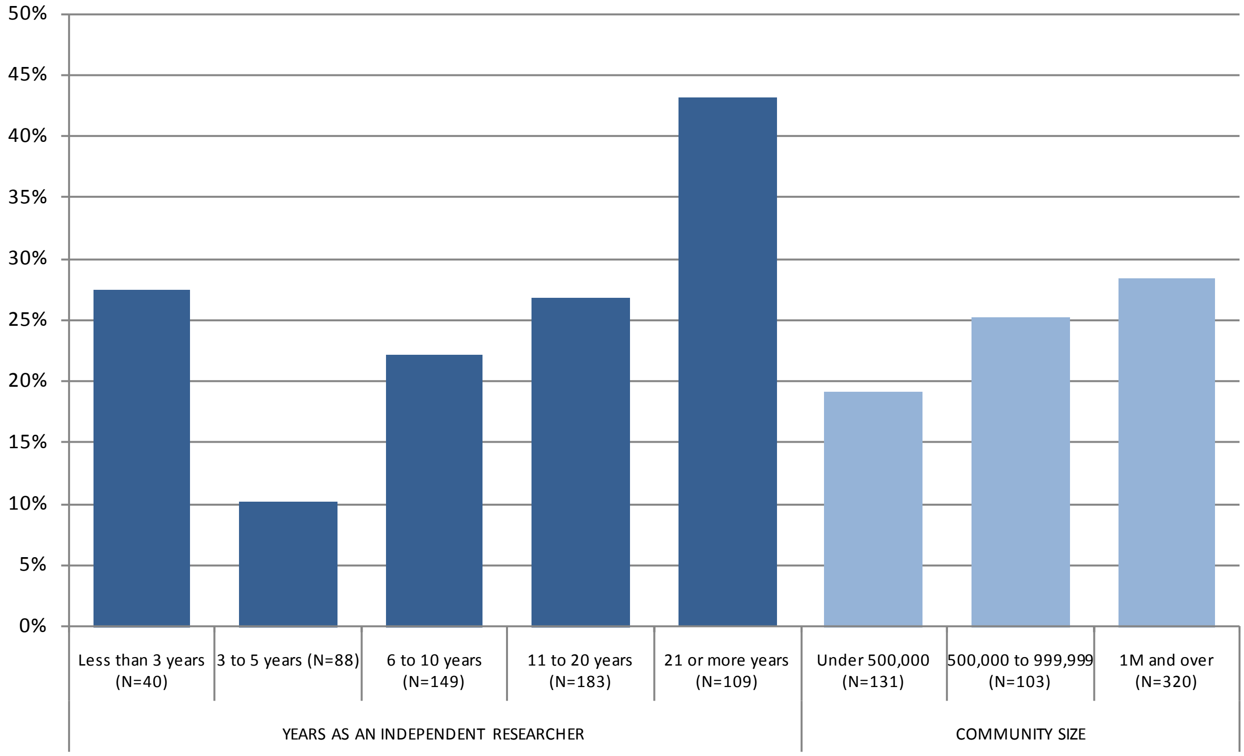


3.7 BALANCE OF GRANTS IN TERMS OF SIZE AND QUANTITY – RESEARCHER SURVEY

Respondents of the researcher survey were asked to indicate whether it was better for cancer funding organizations to offer more grants of smaller sizes or fewer, larger grants. Most respondents (73.5%) supported more grants of smaller sizes. While males and females did not differ in their responses to this item, responses did vary by years of independent research experience and community size (Figure 3.7.1). Support for fewer grants of larger sizes was highest for researchers with the most seniority (21 or more years as an independent researcher), with respondents with the least experience having the second proportionately highest support for fewer grants. Similarly, increasing age of respondents was associated with increased support for fewer grants of larger sizes (not shown). To a less marked degree, the trend for increased support of fewer grants of larger sizes also increased as community size increased.

FIGURE 3.7.1

PROPORTION OF RESPONDENTS SUPPORTING FEWER GRANTS OF LARGER SIZES BY CHARACTERISTICS - RESEARCHER SURVEY

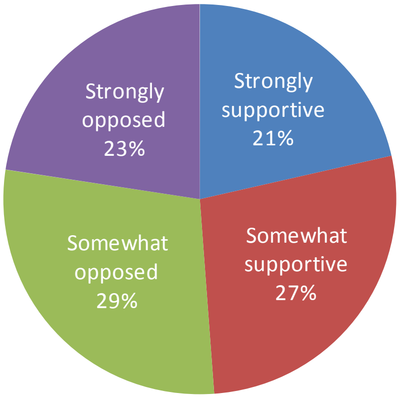


3.8 SUPPORT FOR INCREASED AWARD TERMS – RESEARCHER SURVEY

Respondents of the researcher survey were asked about the extent to which they would support a move to increase the percentage of research awards with a longer term (more than 5 years). A 4-point scale (1-strongly support to 4-strongly oppose) was used for this question. Responses were fairly evenly distributed across the four categories (Figure 3.8.1). There were no differences in ratings by respondents with different characteristics.

FIGURE 3.8.1

DISTRIBUTION OF RATING OF SUPPORT FOR INCREASED AWARD TERMS - RESEARCHER SURVEY



3.9 SUPPORT FOR COLLABORATION AMONG CANADA'S CANCER RESEARCH FUNDERS – RESEARCHER SURVEY

Researchers were asked to indicate from three options how Canada's cancer research funding organizations should collaborate.

Common/Shared Peer-Review Processes

Over two-thirds of respondents (67.6%) saw value in funding organizations using common/shared peer-review processes. Male and female respondents did not differ in their level of support for this option and there were no differences in responses by age group, years of experience, community size or area of expertise.

Co-funding Major Initiatives

Two-thirds of respondents (68.1%) supported co-funding of major initiatives. Proportionately more female (77.3%) than male (63.9%) respondents supported co-funding major initiatives as a strategy for collaboration for Canada's cancer research funders. Researchers with 6 to 10 years of experience had the lowest level of support (54.1%) for co-funding, a level of support statistically significantly lower than all other groups except for the researchers with less than 3 years experience. Co-funding initiatives garnered the least support (59.5%) from researchers aged 35 to 49 years of age and the most support (79.0%) from researchers aged 50 to 69 years of age. There were no differences by community size. These results are summarized in Table 3.9.1.

TABLE 3.9.1

SUPPORT FOR CO-FUNDING MAJOR INITIATIVES (NUMBER AND PERCENT)

CHARACTERISTIC		N	%
SEX	Female	153/198	77.3
	Male	242/379	63.9
YEARS OF EXPERIENCE	Less than 3 years	28/41	68.3
	3 to 5 years	57/89	64.0
	6 to 10 years	85/157	54.1
	11 to 20 years	144/190	75.8
	21+ years	85/110	77.3
AGE GROUP	Under 34	6/8	75.0
	35 to 49	184/309	59.5
	50 to 69	203/257	79.0
	70 and older	3/4	75.0

Among respondents who indicated Biology as an area of expertise, 62.0% supported co-funding major initiatives. This was statistically significantly lower than the level of support indicated by respondents of all other areas of expertise. Respondents who indicated Cancer Control, Survivorship, Outcomes Research & Health Services as an area of expertise had the highest level of support for co-funding at 79.7%.

Organizing Distinct Funding Programs

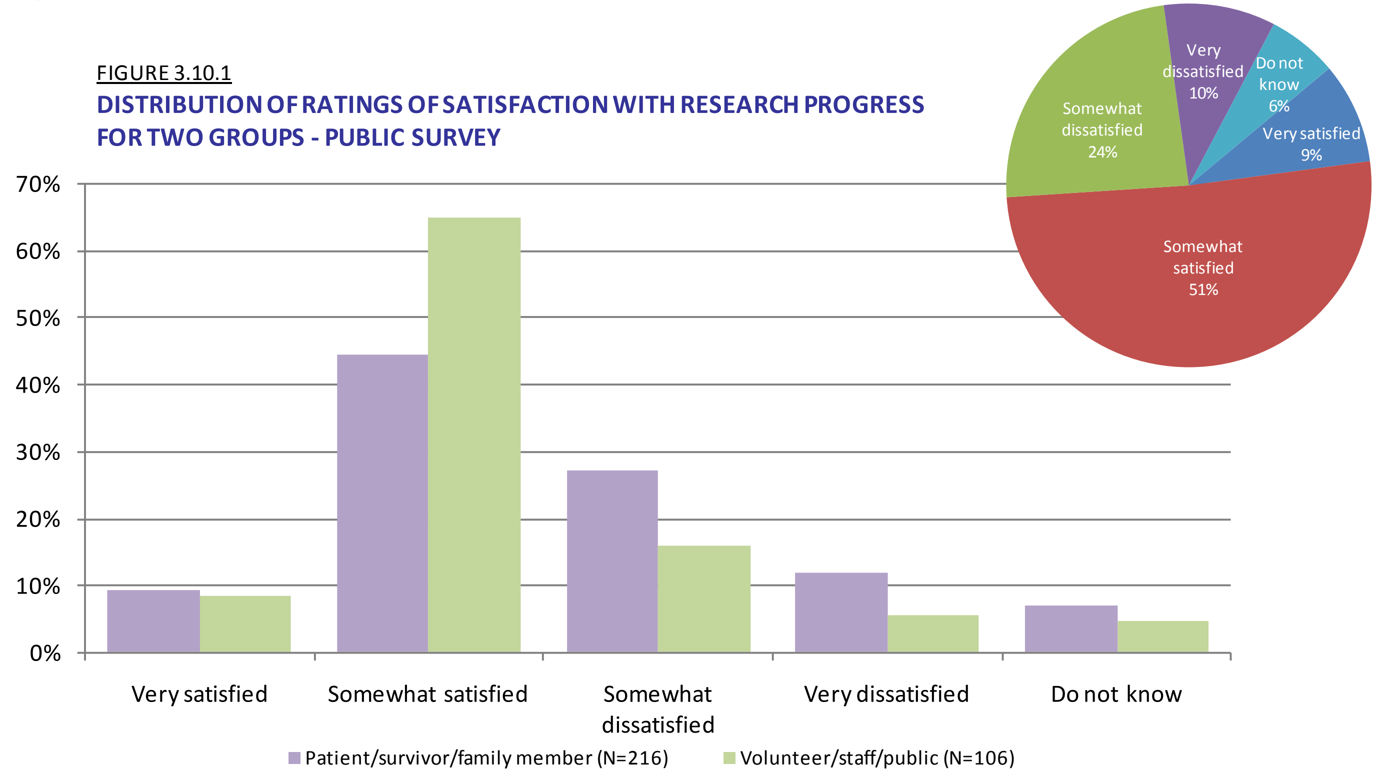
Two of every five respondents supported organizing distinct (non-overlapping) funding programs by research funders—the lowest level of support for the three collaborative options identified in the survey. Male and female respondents did not differ in their level of support for this option and there were no differences in responses by age group, years of experience, community size or area of expertise.

3.10 SATISFACTION WITH RESEARCH PROGRESS – PUBLIC SURVEY

Respondents of the public survey were asked to rate their satisfaction with the progress being made in research on a four-point scale. A "do not know" option was also provided. Three of every five respondents indicated that there were satisfied (somewhat or very) with the progress being made in cancer research, with 20 respondents (6.2%) indicating "do not know" for this question. Volunteer/staff/public respondents were proportionately more likely to indicate that they were "somewhat satisfied" with research progress when compared with patients/survivors/family members (Figure 3.10.1). This was especially the case for volunteers/staff.

FIGURE 3.10.1

DISTRIBUTION OF RATINGS OF SATISFACTION WITH RESEARCH PROGRESS FOR TWO GROUPS - PUBLIC SURVEY



3.11 GAPS AND OPPORTUNITIES – PUBLIC SURVEY

Respondents were asked in an open-ended format to identify the most significant gaps in Canada's current cancer research activities. A total of 232 out of 326 respondents answered this question. A content analysis of responses was undertaken and responses were grouped into three major themes:

- a gap in a particular area, type or focus of research
- a gap or weakness in terms of the way that research was conducted/research funding was administered
- a gap in resources

Results are summarized in Table 3.11.1. An average of 1.3 responses was generated per respondent.

For over half of the responses (59.1%), the gaps identified were in specific areas of research (including specific cancers). A need for more cancer prevention research emerged as a main theme (14.3% of all responses) and it was strongly related to the weighting of prevention research in the research allocation question (i.e., respondents who identified prevention research as a gap gave higher mean investment allocations to prevention research). Overall, proportionately more volunteers/staff/public than patients/survivors/family members identified a process gap (30.8% compared to 24.1%).

TABLE 3.11.1

SIGNIFICANT GAPS IN CANADA'S CURRENT CANCER RESEARCH ACTIVITIES – PUBLIC SURVEY

GAP IDENTIFIED		**Patient/survivor/ family member**		**Volunteer/staff/ public**		**TOTAL [1]**	
		N	**%**	**N**	**%**	**N**	**%**
SPECIFIC AREA/TYPE/ FOCUS OF RESEARCH	• cancer prevention research	26	13.1	18	16.8	44	14.3
	• research on specific cancers, including rarer cancers/address inequitable distribution of site-specific research investment	18	9.0	9	8.4	28	9.1
	• research on supportive care, survivorship, and end-of-life	17	8.5	7	6.5	24	7.8
	• research on access to care, wait times, and health disparities	13	6.5	6	5.6	19	6.2
	• cancer treatment research, including a focus on curative treatment as well as research on the side effects and long-term impacts of cancer treatments	12	6.0	6	5.6	18	5.8
	• research on early detection, diagnosis, and screening	11	5.5	2	1.9	13	4.2
	• research focused on cancer and the environment	7	3.5	3	2.8	10	3.2
	• research focused on young adults with cancer	6	3.0	2	1.9	9	2.9
	• clinical research and clinical trials	2	1.0	1	0.9	3	1.0
	• research on cancer stem cells	0	0.0	2	1.9	2	0.6
	• research in other specific areas of research	7	3.5	5	4.7	2	0.6
PROCESS	• lack of collaboration/coordination within the scientific community	16	8.0	11	10.3	27	8.8
	• lack of knowledge dissemination/communication of research findings to the public	12	6.0	6	5.6	18	5.8
	• need to accelerate translation of research findings to the clinic/for the patients' benefit	11	5.5	5	4.7	16	5.2
	• need to improve/make more efficient the research enterprise/research funding process	4	2.0	7	6.5	11	3.6
	• lack of patient/survivor involvement/input	3	1.5	3	2.8	6	1.9
	• lack of innovation	2	1.0	1	0.9	3	1.0
RESOURCES	• general lack of funding for research	18	9.0	8	7.5	26	8.4
	• need to augment researcher capacity	6	3.0	2	1.9	8	2.6
	• lack of support for tumour banks/biospecimen repositories	2	1.0	0	0.0	2	0.6
OTHER	Not classified elsewhere	6	3.0	3	2.8	9	2.9
TOTAL		**199**	**100**	**107**	**100**	**308**	**100**

[1] Two responses from two respondents who did not identify their perspective are included in the Total column.

Respondents were also asked to identify the most significant opportunities in the future for Canada to contribute to cancer research internationally. A total of 191 out of 326 respondents answered this question. A content analysis of responses was undertaken. Responses were grouped into three major themes, the first two of which were very similar to the first two themes identified under “gaps”:

- an opportunity to contribute to a specific research area
- an opportunity to improve the current way that research was conducted/research funding was administered
- an opportunity to utilize existing Canadian resources

Results are summarized in Table 3.11.2. An average of 1.3 responses was generated per respondent.

TABLE 3.11.2

SIGNIFICANT OPPORTUNITIES FOR CANADA TO CONTRIBUTE TO CANCER RESEARCH INTERNATIONALLY – PUBLIC SURVEY

OPPORTUNITY IDENTIFIED		Patient/survivor/ family member		Volunteer/staff/ public		TOTAL [1]	
		N	%	N	%	N	%
CONTRIBUTING TO SPECIFIC RESEARCH AREAS	• treatment research, including complementary approaches	13	7.6	2	2.5	16	6.3
	• cancer prevention, including holistic approaches	5	2.9	8	9.9	13	5.1
	• stem cells and cancer stem cells	9	5.3	4	4.9	13	5.1
	• biomarkers, imaging, diagnostics, and early detection	11	6.5	0	0.0	12	4.7
	• supportive care, survivorship, and end-of-life	7	4.1	4	4.9	11	4.3
	• genomics research	8	4.7	2	2.5	10	3.9
	• basic biology/cancer biology research	5	2.9	3	3.7	8	3.1
	• clinical research and clinical trials	4	2.4	2	2.5	6	2.4
	• alternatives to address the shortage of medical isotopes	5	2.9	0	0.0	5	2.0
	• translational research	1	0.6	1	1.2	2	0.8
	• research on vaccines	2	1.2	0	0.0	2	0.8
IMPROVING PROCESS	• advancing research findings through knowledge dissemination/transfer	28	16.5	11	13.6	39	15.4
	• promoting collaborative research and shared resources (de-emphasizing competition)	18	10.6	11	13.6	29	11.4
	• focusing research efforts, including centralizing resources/leadership, and improving efficiencies	15	8.8	8	9.9	23	9.1
	• enhancing funding and researcher capacity	11	6.5	8	9.9	19	7.5
PLAYING TO CANADIAN STRENGTHS	• showcasing the high quality of Canadian research and researchers	6	3.5	5	6.2	11	4.3
	• utilizing Canada's ethnic diversity and centralized health care delivery system within the conduct of research	5	2.9	4	4.9	9	3.5
OTHER	Not classified elsewhere	17	10.0	8	9.9	26	10.2
TOTAL		**170**	**100**	**81**	**100**	**254**	**100**

[1] Three responses from two respondents who did not identify their perspective are included in the Total column.

Overall, two of every five respondents indicated that there was an opportunity for Canada to contribute by improving the dissemination of research findings to other researchers and to the general public and by promoting collaboration and increased efficiencies within the research enterprise. Patients/survivors/family members were proportionately more likely to identify a specific research area as an opportunity when compared with volunteers/staff/public (41.2% compared to 32.1%). Volunteers/staff/public were proportionately more likely to identify Canadian-specific strengths in terms of the quality of its research and researchers, its ethnic diversity and its health care delivery system (11.1% compared to 6.5%).

4. DISCUSSION

Although the results of the surveys are preliminary, several themes emerged that are worthy of further exploration.

Investment allocation and funding balance – perspective matters!

Not all survey respondents shared the same viewpoints of how research investment should be allocated. The data revealed substantial differences in the opinions of researchers and the public in terms of the research dollars that should be allocated to the areas of Biology and Cancer Control, Survivorship, Outcomes Research & Health Services. There were also some distinct differences in responses on the public survey when stratified by respondent sex and perspective and on the researcher survey when stratified by respondent sex and expertise—in some cases, the sex differences found in the public and researcher surveys were in the opposite direction. Males responding to the public survey regardless of perspective gave the highest allocation for research in the area of survivorship/palliation and we believe that this finding should be investigated to determine if it reflects an actual experiential/perceptual difference or an artifact of our small, non-representative survey sample.

The surveys also revealed converging opinions in terms of how the investment in cancer research should be distributed in the areas of Early Detection, Diagnosis & Prognosis, Etiology/Causes, and, to a lesser extent, Prevention and Treatment. Although researchers tended not to support strategically-based funding competitions, there may be some openness to focused competitions in areas like Early Detection, Diagnosis & Prognosis and Prevention, where there was a demonstrated gap between the actual research investment and what was perceived as important from a science or societal point of view.

In terms of funding balance, one in three researchers based in larger communities favoured concentrating research funding to leading institutes. Respondents to the public survey thought that a balanced approach was key. Indeed, the appetite to concentrate the funding diminished somewhat as community size increased for respondents to the public survey while an opposing trend occurred among researchers. It should be noted, however, that the respondents to the researcher survey were not given the balanced approach option and this may have influenced the observed difference.

The patient voice in research priority setting

The *Maximizing Patient Voices Project* undertaken by the Canadian Cancer Action Network in 2007-08 documented the involvement of patient representatives in some cancer agencies and the benefits gained from their involvement. The project found a diversity of approaches to engaging patients and no single formula for success.

There was a high level of interest in being involved in the research agenda setting. Nearly nine of every ten cancer respondents to the public survey felt that non-scientists should be formally involved or involved in an ongoing way.

Researchers were asked a very different kind of question about stakeholder involvement—they were asked to rank the importance of input from multiple stakeholders in the research priority setting process. There was nearly unanimous support that researchers were the most important stakeholders, with about one of every 20 researchers ranking patients/survivors/family members as “most important.” In terms of mean ratings of importance, patients/survivors/family members ranked second after researchers, although only negligibly more important than the other stakeholders listed. Without comparable data, it is difficult to assess the degree to which opinions from researchers and the public converge on role of the public within the research priority setting process.

Collaboration among funders and communication with the public

Many respondents to the public survey indicated that there was a strong need to improve communication with the public about research findings as well as enhance collaboration/coordination among researchers and research funders. The majority of researchers supported the implementation of common/shared peer-review processes and co-funding for major initiatives. In terms of other suggestions, some respondents indicated that use of a common application form by research funders may help to streamline the application process.

The pan-Canadian cancer research strategy is designed to improve collaboration/coordination among research funders. In the evaluation process of the strategy, it may be useful to re-survey both stakeholder groups in a few years time to see if and how perceptions of practice have changed.

Matching funding mechanism to research area

The vast majority of respondents to the researcher survey felt that single operating grants were the most important mechanisms to fund cancer research, and this was especially the case for researchers working in the areas of Biology, Etiology/Causes, and Early Detection, Diagnosis & Prognosis. Team grants/program projects were also supported.

Researchers with expertise in Cancer Control, Survivorship, Outcomes Research & Health Services indicated a stronger preference for career awards and institute support than researchers working in other fields. Supporting researchers from different disciplines may be best accomplished through different funding mechanisms.

Satisfaction with research progress

Overall, respondents to the public survey tended to be satisfied with the progress that had been made in terms of cancer research. Patients/survivors/family members, however, expressed a lower overall satisfaction than volunteers/staff/public and this finding may be worth pursuing within the context of more in-depth information gathering such as a focus group process.

Future surveys

Enhancing survey uptake is particularly important for the public survey. Broader survey promotion particularly within Quebec may help to improve response rates and representativeness. Of note, the Canadian Breast Cancer Research Alliance was able to achieve a sample of over 800 using an online survey that had a time window of 20 days. They did this by involving 11 different breast cancer organizations in the promotion of the survey.[9] A more extensive promotional approach may not only help to increase the number of respondents but may improve the representativeness of the survey sample. Use of closed-ended items and only a very few judiciously chosen open-ended items may also help to increase the response rate.

Future surveys of cancer researchers would also benefit from strategies to improve response rates. Discerning the issues underlying reluctance to identify provincial affiliation is also important.

The surveys herein were designed independently, without the intention that the results would be compared, so similar constructs were assessed with different questions in each survey. A more forward-looking approach would incorporate identical overlapping questions in order to ensure that comparative analysis could be conducted.

And finally, as mentioned above, use of mixed methodologies (i.e., online surveys, which also recruit interested respondents for focus groups) may be helpful in addressing the "whys" of response pattern variations. Taking this a step further, The Macmillan Listening Study (previously mentioned) involved cancer patients in the design, execution and analysis of its study. This may be an avenue worth investigating in the design of future surveys.

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[9] *Breast Cancer Research Priorities: A Survey of Survivors and Others Involved in Breast Cancer*, by Brian Rush and Nancy Dubois published May 2008 and commissioned by the Canadian Breast Cancer Research Alliance.

APPENDIX A. Survey for Patients, Survivors, and Concerned Members of the Public

Weigh in on cancer research spending in Canada

Your input on cancer research spending in Canada will help shape the first-ever Pan-Canadian Research Strategy to increase collaboration, eliminate duplication, and, ultimately, speed discoveries that have the potential to benefit all Canadians. Led by the Canadian Cancer Research Alliance (CCRA), a network of Canada's cancer research granting agencies funded by the Canadian Partnership Against Cancer, this survey is meant for anyone who has been touched by cancer; people with cancer, survivors, family members, cancer organization volunteers and concerned members of the public are encouraged to complete it.

Fifteen minutes of your time can contribute to a new approach to cancer research funding in Canada. All answers are strictly confidential. Only completed surveys will be included in the results. Once you have entered your responses press "Submit responses." To ensure fair representation of all participants, submit your survey only once.

Answers to the survey questions are private. You will not be asked to provide your name, or any other information that could be used to identify you individually. You will be asked to describe yourself in general ways, including identifying your province, gender and age range. This information will help the CCRA analyze survey results.

Please click here to begin: [Survey Link]

About the Canadian Cancer Research Alliance

The Canadian Cancer Research Alliance (CCRA) is a network of Canada's cancer research granting agencies. Currently it has 23 members, including federal research funding bodies (e.g. Institute of Cancer Research at the Canadian Institutes of Health Research), provincial agencies (e.g. B.C. Cancer Agency), and not-for-profit organizations (e.g. Canadian Cancer Society). Collectively, these organizations invest over $400 million in cancer research each year.

CCRA member organizations are currently working together to develop a Pan-Canadian Cancer Research Strategy. This is a new initiative for cancer research funding bodies. In previous years, CCRA members have shared information but have not shared common strategy. CCRA member organizations believe that through enhanced collaboration and coordination, they can use existing research funds more efficiently and accelerate discoveries that reduce the incidence of cancer, lead to a better quality of life for those living with cancer and reduce the rate of cancer mortality in Canada.

CCRA is conducting a national consultation process to ensure that all stakeholders contribute to the design of the new national strategy. This survey is one way in which CCRA is reaching out to consult cancer patients, survivors, family members, cancer organization volunteers and other members of the public. Please take a few minutes to complete the survey and participate in this important process. To begin, please click here.

For more information on CCRA, visit: www.ccra-acrc.ca

1. Consider the choices faced in allocating funds for research. Rate the importance of each category of cancer research by imagining you have $100 dollars to distribute across these eight categories. Fill in amounts beside each category to make up $100.

BIOLOGY: Research on how normal cells and cancer cells develop and function. An example would be research that explains how tumours spread to other parts of the body.

CAUSES: Research that aims to identify the causes of cancer including hereditary/genetic factors, lifestyle factors and environmental factors. An example would be research that confirmed smoking causes lung cancer.

PREVENTION: Research that aims to find ways of stopping cancer before it starts. This can include lifestyle changes associated with decreased cancer rates, use of vaccines to immunize against viruses associated with certain types of cancer, or the use of chemopreventive drugs. An example would be research that confirmed the HPV vaccine reduces the risk of cervical cancer.

EARLY DETECTION, DIAGNOSIS & PROGNOSIS: Research that focuses on identifying and testing 'biomarkers' and imaging methods that are helpful in detecting and/or diagnosing cancer as well as predicting the outcome or chance of recurrence. An example would be the development of a blood test that indicates the presence of certain types of cancer in the body. ☐

TREATMENT: Research on various cancer treatment strategies including new surgical techniques, cancer drugs and radiation. An example would be research that shows that a certain drug slows down the growth of a certain tumour type. ☐

BEHAVIOUR & COMMUNICATION: Research on the influence of behaviours and attitudes relating to cancer control, including interventions to promote psychological adjustment to a diagnosis of cancer, as well as research on communication and educational strategies for patients and health care providers. An example would be a study on the kind and format of information that would be useful to cancer patients making decisions regarding their treatment. ☐

HEALTH SERVICES: Research on how to improve the quality of health care delivery, access to appropriate cancer care, and cost effectiveness of health care services. An example would be a study of the costs of different kinds of cancer screening tests. ☐

SURVIVORSHIP & PALLIATION: Research on how to improve the quality of life for cancer patients and survivors, support families, and provide supportive end-of-life care. An example would be research on improving pain management in patients with advanced cancer. ☐

2. Why did you allocate the funding the way you did? What were the key factors that influenced your decision making?

3. Is it important to spread research funding across provinces, universities, academic hospitals and other research institutes? Or, is it better to concentrate funding, for example at national centres for excellence?

- ○ Spread the funding across the country
- ○ Concentrate the funding to leading institutes
- ○ Balance between some local funding and concentrated funding

Please explain your choice:

4. What role should knowledgeable non-scientists play in setting research priorities?

- ○ Occasional consultation
- ○ Ongoing consultation
- ○ Formal involvement within the processes used by organizations that fund cancer research

Please explain your choice:

5. From your perspective as a patient, survivor, family member or other concerned stakeholder, how satisfied are you with the progress being made in cancer research?

- ○ Very satisfied
- ○ Somewhat satisfied
- ○ Somewhat dissatisfied
- ○ Very dissatisfied
- ○ Do not know

Please explain your choice:

6. What do you see as the most significant gaps in Canada's current cancer research activities?

7. What do you see as the most significant opportunities in the future for Canada to contribute to cancer research internationally?

8. Please identify yourself by checking one box only:

- ○ A. Cancer patient (currently being treated)
- ○ B. Cancer survivor (received treatment in the past)
- ○ C. Family member of cancer patient or survivor
- ○ D. Volunteer or staff member at a cancer organization
- ○ E. Concerned member of the public

If [D], please specify the organization

9. Please identify your province/territory, community/city size, gender, and age range. This information will be used to determine how well the survey reflects opinions from across the country.

Province/Territory : Alberta; British Columbia; Manitoba; New Brunswick; Newfoundland & Labrador; Northwest Territories; Nova Scotia; Nunavut; Ontario; Prince Edward Island; Quebec; Saskatchewan; Yukon

Community/City Size : Rural area/low population density; Population under 10,000; 10,000-99,000; 100,000-499,000; 500,000-1,499,000; 1,500,000 and over

Gender : Male Female

Age Range : 19 and under; 20-34; 35-49; 50-69; 70 and older

APPENDIX B. Survey for Researchers

Section 1 – Introduction

1.1 Why This Survey Matters

The Canadian Cancer Research Alliance (CCRA) is an alliance of Canada's 23 major cancer research granting agencies. CCRA members include federal research funding bodies (e.g., CIHR's Institute for Cancer Research), provincial agencies (e.g., B.C. Cancer Agency), and not-for-profit organizations (e.g., Canadian Cancer Society). Collectively, these organizations invest over $400 M in cancer research each year. For more information on CCRA please see www.ccra-acrc.ca.

CCRA member organizations are currently working together to develop a Pan-Canadian Cancer Research Strategy. CCRA member organizations believe that through enhanced collaboration and coordination, they can use existing research funds more efficiently and accelerate discoveries that mitigate the burden of cancer in Canada. CCRA is conducting a national consultation process to ensure that all stakeholders contribute to the design of the new national strategy. This web based researcher survey is an important part of this consultation: we need your help so the voice of the research community is included in our work!

1.2 Privacy Policy

Your answers to the survey questions are private. You will not be asked to provide your name, or any other information that could be used to identify you individually. You will be asked to describe yourself in general ways, including identifying the province where you live, your gender and your age range. This information will enable CCRA to analyse the survey results. For more information on SurveyMonkey, the website service used to disseminate this survey and its security procedures, please see www.surveymonkey.com/Monkey_Privacy.aspx.

1.3 How to Complete this Survey

This survey should take no more than 15 minutes. It is designed to be completed in one session. You begin by clicking on "Next" (see below) which takes you to the survey questions. Answer all the questions and then click on "Done" to submit your responses. Only completed surveys will be included in the results.

Section 2 – Survey Questions

1. Taken together, CCRA members invest approximately $400 M in cancer research each year. How would you allocate this total annual investment across the Common Scientific Outline (CSO) categories? Use percentages so that the combined total for all 6 selections equals 100%. For a detailed description of these categories see www.cancerportfolio.org/cso.jsp.

Biology	
Etiology	
Prevention	
Early Detection, Diagnosis, and Prognosis	
Treatment	
Cancer Control, Survivorship, Outcomes Research, Health Services	

2. What considerations guided your allocation across these CSO categories?

3. Research granting agencies can support research programs in a number of different ways, ranging from operating grants to infrastructure support to career awards. Some research granting agencies also provide funding opportunities in collaboration with other parties. Please tell us your level of support for the following different granting approaches. Please rank these from "1" to "7"; with "1" representing the type of funding that you think is most important and "7" representing the least important.

Single Operating Grants (to individuals or teams)					
Team Grants/Program Project Grants (for multiple projects by a team of investigators)					
Trainee awards					
Career awards					
Equipment or infrastructure awards					
Institute support (e.g. centres of excellence)					
Co-sponsoring research opportunities between two or more granting agencies					

4. What is the optimal balance between project funds awarded via open investigator-initiated competitions and project funds awarded with reference to strategic considerations (e.g. envelope of funds for a specific site)? Use percentages so that the two numbers combine to equal 100%.

Open investigator-initiated competition

Strategic considerations

5. What considerations guided you in suggesting these percentages?

6. Is it important to spread research funding across provinces, universities, academic hospitals and other research institutes? Or, is it better to concentrate funding, for example, at national centres?

○ Concentrate the funding
○ Spread the funding

Please explain your choice:

7. In an era of scarce funding for cancer research, do you believe it is better for the cancer research funding organizations to have more grants available of smaller sizes or fewer, larger grants?

○ Fewer grants of larger sizes
○ More grants of smaller sizes

Please explain your choice:

8. Would you support a move to increase the percentage of research awards that have a longer term (more than 5 years)?

- ○ Strongly Supportive
- ○ Somewhat Supportive
- ○ Somewhat Opposed
- ○ Strongly Opposed

Please explain your choice:

9. Who should have significant input into setting Canada's cancer research priorities? Please rank these from "1" to "5", with "1" representing the group should have <u>the most significant</u> input and "5" representing the group that should have <u>the least</u> input.

Major donors
Patients/survivors/family members
Policy makers
Administrators of granting agencies
Researchers

Other (please specify)

10. How should Canada's cancer research funding organizations collaborate? Please check all that apply:

- ☐ Common/shared peer-review processes
- ☐ Co-funding major initiatives
- ☐ Organizing funding programs distinctly (no overlap of funding)

Other suggestions:

Section 3 – About Yourself

The last few questions ask for details about you. This will help us analyze the results obtained from the survey

1. Again, with reference to the CSO categories, what is your primary area of research interest and expertise? (Check all that apply)

- ☐ Biology
- ☐ Etiology
- ☐ Treatment
- ☐ Cancer control, survivorship, outcomes, health services
- ☐ Prevention
- ☐ Early detection, diagnosis and prognosis

2. How many years have you been active as an independent investigator in cancer research?

- ○ 0-3
- ○ 3-5
- ○ 6-10
- ○ 11-20
- ○ 21+

3. Please identify your province, community size, gender and age range:

Province/Territory : Alberta; British Columbia; Manitoba; New Brunswick; Newfoundland & Labrador; Northwest Territories; Nova Scotia; Nunavut; Ontario; Prince Edward Island; Quebec; Saskatchewan; Yukon

Community/City Size : Population under 500,000; 500,000 to 999,999; 1M and over

Gender : Male Female

Age Range : Under 34; 35-49; 50-69; 70 and older