Minnesota Cancer Alliance

2020 Engagement Survey

The Minnesota Cancer Alliance (MCA) is a coalition of individuals and organizations from varying backgrounds and disciplines, from prevention and detection to treatment, survivorship, and end-of-life care, who are dedicated to reducing the burden of cancer in Minnesota. Individuals and organizations can become official members of the MCA, and the MCA also includes interested individuals who may attend MCA events, stay up-to-date on MCA activities, or who are otherwise working in their communities toward goals or objectives of the Minnesota Cancer Plan 2025.

In July 2020, an engagement survey was sent to 1,041 people from the MCA mailing list. The survey included questions about how people were involved in the MCA, benefits of involvement, MCA functioning and impact, and how the MCA could be improved. A total of 138 people completed the survey for a response rate of 13%. A similar, longer survey was done in May 2019; 121 (11%) responded last year.

Because of the wide array of experiences respondents had with the MCA, respondents were divided into three groups for analysis. "Involved" respondents were those who said they were a current MCA member or were on a committee, network, or Strategy Action Group (45% of respondents; based on responses in Figure 1, similar to last year). "Interested" individuals included people who were involved in the MCA in other ways, but who were not current members or serving on a committee, network, or Strategy Action Group (39% of respondents). Respondents who were "not involved" said that they had not been involved with the MCA in the past year (17% of respondents).[1]

In the summary below, responses are reported for the "involved" and "interested" groups combined. When responses varied across the two groups, the differences are noted. In cases where this is not noted, the responses were generally comparable. The full set of findings can be found in Appendix A.

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[1] Respondents who selected that they were not involved in the MCA in the last year were skipped to a set of open-ended questions at the end of the survey about what might help them become more involved in the MCA. Accordingly, the percentages described below reflect only the "involved" and "interested" groups.

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Key findings

- **Most respondents felt that Minnesota is better off today because of the MCA and that they benefitted from being involved.** Seventy-four percent of respondents strongly agreed or agreed that the MCA has a greater impact on the cancer burden than individual organizations could have, up from 65% last year (Figure 5). In addition, 97% of respondents reported receiving some benefits from their involvement in the MCA. The most important benefits people reported were staying informed about cancer-related resources, initiatives, and programs, and making connections with people from other organizations. About three-quarters (72%) of respondents said they used the Cancer Plan or MCA resources in their work (76% of "involved" and 67% of "interested" respondents; Figure 6). However, in the open-ends, some respondents shared concerns that the MCA lacks direction and clear objectives.

- **While respondents said they were informed as often as they should be about what was going on with the MCA, many would also like more updates about Cancer Plan progress and efforts across the state.** Most (75%) respondents reported that they were informed as often as they should be about what is going on in the MCA (81% of the "involved" group agreed with this statement and 68% of the "interested" group; Figure 4). However, in the open-ended questions, respondents mentioned a need for more information about progress towards the Cancer Plan objectives, what organizations across the state are doing, and ways to get involved. The email newsletter was the most frequently reported way that people stayed involved in the MCA (46% of respondents reported reading the newsletter regularly, with 61% of "involved" and 49% of "interested" respondents; Figure 1). When asked about the most memorable email from the MCA, most respondents said that all of them were informative, or specifically mentioned updates from the Cancer Health Equity Network, the MCA's policy work, and event notices for the Cancer Summit.

- **The MCA can play a strong connecting role across the state.** Members – particularly "involved" respondents – reported that one of the main benefits of MCA involvement was connections to other organizations (80% of "involved" respondents reported this as a benefit compared to 34% of "interested" individuals; Figure 3). When asked what would help them become more involved or how the MCA could better support their work, many respondents mentioned more opportunities to connect with other members. Respondents suggested both opportunities for informal, social connections, as well as ways the MCA could support collaboration across common issue areas. Several respondents also suggested the MCA could play a lead coordinating role in addressing health equity, especially with the recent increased attention placed on racial disparities and health.

> *Perhaps a virtual communication platform like Slack (or even a facilitated email thread) where members could share resources and ask questions of one another.*
>
> *Provide more funding for Strategy Action Groups to support activities that address objectives in the cancer plan.*
>
> *Somehow to gather information about what others are doing in this space so we can coordinate with others. Like a clearinghouse.*

> *Convene mini-conferences around EACH of the different goals of the cancer plan - to deep dive into what each group is doing; what has changed since COVID; brainstorm how we can get back on track to make progress on the goals.*

- **Respondents were interested in a virtual meeting to provide an orientation for new and returning members and opportunities to network.** When asked about their preferred format for an orientation and networking event for members, respondents rated a virtual meeting with a short presentation and where members could see each other the highest (44% rated this their first preference; Figure 7). In open-ended responses, they suggested having opportunities for people to connect through break-out rooms or contact lists for people to follow up with each other afterwards. Several also were interested in using some of the time for members to provide input into the direction of the MCA and how the MCA can engage members to move forward with their collective goals.

- **The MCA can continue to broaden engagement, especially in greater Minnesota, and provide more information on how members can become involved.** Survey respondents represented a variety of roles, with most in public health (26%), research (23%), or patient/survivor advocacy and support roles (22%; Figure 9). Respondents also represented a wide variety of focus areas covering all the Cancer Plan objectives. Areas with the greatest representation were: breast, cervical, and colorectal cancer screening (41%), support services (39%), survivorship care planning (32%), and tobacco use (32%; Figure 10). Radon mitigation (9%), reducing sunburn and indoor tanning (7%), and rehabilitation (5%) were areas with the lowest representation. Most (88%) survey respondents were from the Twin Cities metro area, with other respondents equally divided across other regions of the state (Figure 9). In the open-ended questions, respondents suggested that there may be opportunities to continue to broaden engagement, especially in rural communities, among communities of color, and with professionals working on types of cancer such as urologic cancers or blood cancers that are not directly mentioned in the Cancer Plan. Respondents noted the need for more information about how to become involved and suggested both short-term opportunities and more meaningful opportunities for engagement. Direct recruitment or outreach from current MCA members were mentioned as promising strategies for engaging new members.

> *I think there has always been confusion about who is a member and how they can become members and if membership is somehow "renewed." As a result, I think there are "lurkers" who don't have pride in that membership and are not driven to do anything more than they are. I also suspect there is a feeling of disconnect for people outside the metro unless they are personally driven to remain engaged.*
>
> *Recruit members especially in communities of color in Minnesota.*
>
> *I think MCA has a diverse group that works with them. Maybe members reaching out to others. Or more direct recruitment by MCA.*
>
> *Surveys are good and allow for participation and idea sharing outside of in-person or more labor intensive events.*
>
> *Engage members in setting the agenda for the work group meetings.*

Recommendations

The following recommendations, based on the survey findings, are intended to help the MCA consider ways to best engage and support individuals involved in its work moving forward.

- Provide ongoing updates about progress towards the Cancer Plan, including publicizing the Cancer Plan dashboard update through different platforms (e.g., a newsletter article or webinar).
- Explore new systems, such as an online platform, for members to track work being done around the state and network with one another.
- Continue to publicize how people can become involved and upcoming events, especially through the e-newsletter and website. Offer more frequent networking opportunities, especially through online meetings and presentations and in greater Minnesota.
- Explore opportunities to engage members or support work related to objectives that currently have less representation (e.g., radon mitigation, reducing sunburn and indoor tanning, and rehabilitation).
- Consider what role the MCA can take in being a statewide leader in addressing health disparities related to cancer.

Survey data

In the survey data below, respondents were divided into three groups. “Involved” respondents were those who said they were a current MCA member or were on a committee, network, or Strategy Action Group (Figure 1). “Interested” individuals included people who were involved in the MCA in other ways, but were not current members or serving on a committee, network, or Strategy Action Group. Respondents who were “not involved” had not been involved with the MCA in the past year.

Respondents who said they were not involved in the MCA in the last year were sent to a set of open-ended questions at the end of the survey about what might help them become more involved in the MCA. Percentages in tables may not equal 100% due to rounding.

Involvement

1. How respondents are involved

Please indicate how you were involved in the MCA in the past year. (Check all that apply.)	Involved (N=61)	Interested (N=53)	Not involved (N=23)	2020 Total (N=137)	2019 Total (N=121)
I work at an organization that is a MCA member.	48%	34%	--	34%	50%
I read the MCA monthly e-newsletter regularly.	61%	49%	--	46%	46%
I attended one or more MCA-sponsored events.			--		45%
I stayed up to date about the work of the MCA.	61%	38%	--	42%	36%
I am a current MCA member.	79%	--	--	35%	34%
I shared information about the MCA with people in my organization.	49%	40%	--	37%	31%
I shared information from the MCA with people outside of my organization.	44%	19%	--	27%	22%
My organization collaborated with one or more MCA member organizations on a specific project.	34%	30%	--	27%	22%
I am a member of an MCA committee.	56%	--	--	25%	20%
I have worked on addressing objectives of the Cancer Plan (outside of a Strategy Action Group).	56%	28%	--	36%	16%
I recruited people to participate in MCA projects and activities.	23%	4%	--	12%	12%
I am a member of an MCA network.	8%	--	--	4%	7%

1. How respondents are involved (continued)

Please indicate how you were involved in the MCA in the past year. (Check all that apply.)	Involved (N=61)	Interested (N=53)	Not involved (N=23)	2020 Total (N=137)	2019 Total (N=121)
I was not involved with the MCA in the last year.	--	--	100%	17%	6%
I am a member of an MCA Strategy Action Group.	15%	--	--	7%	4%
I worked on a project supported through Strategy Action funding.	13%	4%	--	7%	NA
Other: retired, newsletter author, 2019 Cancer Summit	0%	8%	0%	3%	3%

2. MCA involvement ("Involved" group only)

	2020	2019
Committee involvement	**(N=34)**	**(N=22)**
CHEN – Cancer Health Equity Network	35%	36%
Policy	26%	27%
Membership and Communications	24%	36%
Steering Committee	21%	64%
Evaluation Advisory	6%	18%
Other: Diversity, Survivorship, and Faces of Tracking through the CDC	12%	--
Network involvement	**(N=4)**	**(N=10)**
Colon Cancer Network	3	6
Commission on Cancer Network	0	4
Other: Community Cancer Leadership Collaborative	1	--
Strategy Action Group involvement	**(N=8)**	**Not asked**
Cancer Care Legal Care	3	--
Clinical Trials	2	--
Human Papillomavirus (HPV)	2	--
American Indian Cancer Foundation (AICAF)	1	--
Angel Foundation	1	--
Colon Cancer Network	1	--
Objective 10 (Lung Cancer Screening)	1	--

Satisfaction and benefits from being involved in the MCA

3. Types of benefits from MCA involvement

What are the three most important benefits you experience from being involved in the MCA? (Select up to three.)	2020 Involved (N=61)	2020 Interested (N=53)	2020 Total (N=114)	2019 Total (N=85)
Staying informed about cancer-related resources, initiatives, and programs	70%	74%	72%	78%
Making connections with people from other organizations	80%	34%	59%	69%
Meeting my own organization's goals by working with others through the MCA	30%	32%	31%	26%
Coordinating resources more effectively with other organizations working on the same issues	28%	23%	25%	26%
Having the opportunity to influence the future direction of the MCA's efforts	33%	11%	23%	21%
Having access to data about cancer that would have been more difficult to obtain otherwise	16%	32%	24%	18%
Receiving resources that I wouldn't have otherwise received	8%	28%	18%	17%
Having opportunities for professional development	5%	13%	9%	13%
Gaining credibility for my organization's work	10%	2%	6%	7%
Other[a]	0%	2%	1%	0%
None, I do not benefit from being involved with the MCA.	2%	4%	3%	--

[a] One person responded, "Being able to collectively improve the health, well-being and productive longevity of Minnesotans."

4. I am informed as often as I should be about what is going on in the MCA.

	2020 Involved (N=61)	2020 Interested (N=53)	2020 Total (N=115)	2019 Total (N=100)
Strongly agree	25%	17%	21%	12%
Agree	56%	51%	54%	62%
Disagree	13%	13%	13%	10%
Strongly disagree	2%	2%	2%	0%
I'm not sure/not applicable	5%	17%	10%	16%

5. The MCA has a greater impact on the cancer burden than individual organizations could have.

	2020 Involved (N=61)	2020 Interested (N=53)	2020 Total (N=115)	2019 Total (N=99)
Strongly agree	36%	23%	30%	25%
Agree	39%	47%	44%	40%
Disagree	10%	4%	7%	6%
Strongly disagree	3%	0%	2%	0%
I'm not sure/not applicable	12%	26%	18%	29%

6. I have used the Cancer Plan or other MCA resources in my work.

	2020 Involved (N=61)	2020 Interested (N=53)	2020 Total (N=115)
Strongly agree	23%	8%	16%
Agree	53%	59%	56%
Disagree	10%	17%	13%
Strongly disagree	3%	0%	2%
I'm not sure/not applicable	12%	17%	14%

Networking and orientation event

The MCA is planning to host an orientation and networking event for new and returning members and was interested in people's preferences for format. They were asked to rate their preferences on three options: a virtual meeting where members could see each other and would include a short presentation; a recorded webinar, with a presentation where members could join live but with limited interaction with one other; and a break-out/early bird session at the Cancer Summit, either virtually or in-person. They were also invited to suggest other ideas.

7. Preferences for networking event and orientation format

The MCA is planning to host an orientation and networking event. Please rate the format(s) you would prefer from most preferred to least preferred.		**Virtual meeting**	**Webinar**	**Break-out/early bird session**
Involved (N=55)	Most preferred	49%	29%	22%
	2nd preferred	29%	29%	42%
	Least preferred	22%	42%	36%
Interested (N=43)	Most preferred	37%	26%	37%
	2nd preferred	44%	40%	16%
	Least preferred	19%	35%	47%
Not involved (N=15)	Most preferred	40%	60%	0%
	2nd preferred	40%	27%	33%
	Least preferred	20%	13%	67%
Total (N=113)	Most preferred	44%	32%	25%
	2nd preferred	36%	33%	31%
	Least preferred	20%	35%	44%

8. Count of open-ended responses by question and theme

	Count
What prevents you or makes it hard to become more involved with the MCA?	
Time and competing priorities, both personal and professional	64
Need more information on how to become involved	16
Concerns about MCA functioning and impact	6
Does not fit with professional role	6
What ideas do you have for how the MCA could support greater engagement among members?	
More opportunities to connect through virtual meetings, social gatherings (when possible), Listserve or facilitated email thread, and sharing member lists	16
Broaden engagement to include more survivors and patients, rural areas, and communities of color, and include members in agenda-setting	12
Provide more information about current efforts and progress to date	9
Support collaborations on specific issue area through short-term engagement opportunities and address specific cancer topics	5
More communication and media/social media	4
Provide more information on how to get involved	3
Nothing/unsure	12
How could the MCA better support your work related to the Cancer Plan?	
Support connections across organizations through the newsletter, mini-conferences around each Cancer Plan objective, and sharing best practices for addressing objectives	9
Share information and regular updates	8
Support specific topic areas, such as adolescent and young adult cancer care, alignment with chronic disease plans, and clinical trials	5
Support outreach and community engagement with communities of color	3
Advocate and support systems change	3
Not sure/not applicable:	20
What is the most memorable email you remember getting from MCA in the last year?	
All of them	8
Committee updates (CHEN, Policy Committee, and Membership Committee)	6
Event notifications	2
Other	7
Not sure	24

Description of respondents

9. Description of 2020 respondents

What region(s) of the state do you work in? (Check all that apply.)	Involved (N=59)	Interested (N=49-50)	Not involved (N=21-23)	Total (N=129-132)
Twin Cities (7-county)	92%	86%	81%	88%
Northwest	12%	14%	5%	12%
Southeast	10%	14%	5%	11%
Central Minnesota	12%	12%	5%	11%
Northeast (Arrowhead)	12%	12%	5%	11%
Southwest	12%	10%	0%	9%
What role do you have in the cancer community? (Check all that apply.)				
Public health professional	31%	24%	17%	26%
Researcher	27%	16%	26%	23%
Patient/survivor advocacy and support services	36%	10%	13%	22%
Medical professional	15%	20%	17%	17%
Survivor	17%	12%	13%	15%
Other non-medical support professional	17%	12%	4%	13%
Volunteer	15%	6%	13%	11%
Current patient	9%	0%	4%	5%
Community health worker or patient outreach	2%	6%	0%	3%
Caregiver	5%	0%	0%	2%
Social worker	0%	4%	0%	2%
Other[a] (please describe)	3%	12%	22%	10%

[a] Other responses included law professor; author and speaker; cancer registry; quality improvement (QI); industry; marketing, communication and outreach; non-profit organization; professional association; and retired medical professional.

10. 2020 respondents' area of work by Cancer Plan objective

Please select the Cancer Plan objective(s) your work most closely aligns with and describe your work in this area (select all that apply).	Involved (N=58)	Interested (N=48)	Not involved (N=17)	Total (N=132)
Cancer prevention				
Reducing commercial tobacco use (objective 11/12)	33%	31%	0%	32%
Reducing obesity, or increasing physical activity/healthy eating (objective 13)	28%	31%	0%	25%
HPV vaccination (objective 14)	22%	19%	0%	18%
Radon mitigation (objective 15)	9%	13%	0%	9%
Reducing sunburn and indoor tanning (objective 16)	7%	8%	0%	7%
Other prevention work	21%	19%	12%	19%
Cancer screening				
Breast, cervical, and colorectal cancer screening (objective 2)	47%	40%	29%	41%
Lung cancer screening (objective 4)	21%	23%	12%	20%
Genetic counseling and testing (objective 3)	12%	19%	18%	15%
Other cancer screening	10%	15%	6%	11%
Patient support and care				
Support services (objective 5)	45%	38%	24%	39%
Survivorship care planning (objective 7)	35%	38%	6%	32%
Clinical trials (objective 10)	40%	17%	29%	29%
Patient navigation (objective 6)	29%	25%	6%	24%
Reducing financial and legal burdens for patients (objective 8)	17%	21%	6%	17%
Advance care planning (objective 17)	12%	21%	6%	15%
Palliative care (objective 18)	16%	19%	0%	15%
Hospice (objective 19)	12%	8%	0%	10%
Rehabilitation (objective 9)	7%	4%	0%	5%
Other cancer patient support or care work	17%	19%	0%	15%
None of these, I do a different type of work	2%	6%	24%	7%

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