

Vaccination decision-making in long-term care: Family and friend survey



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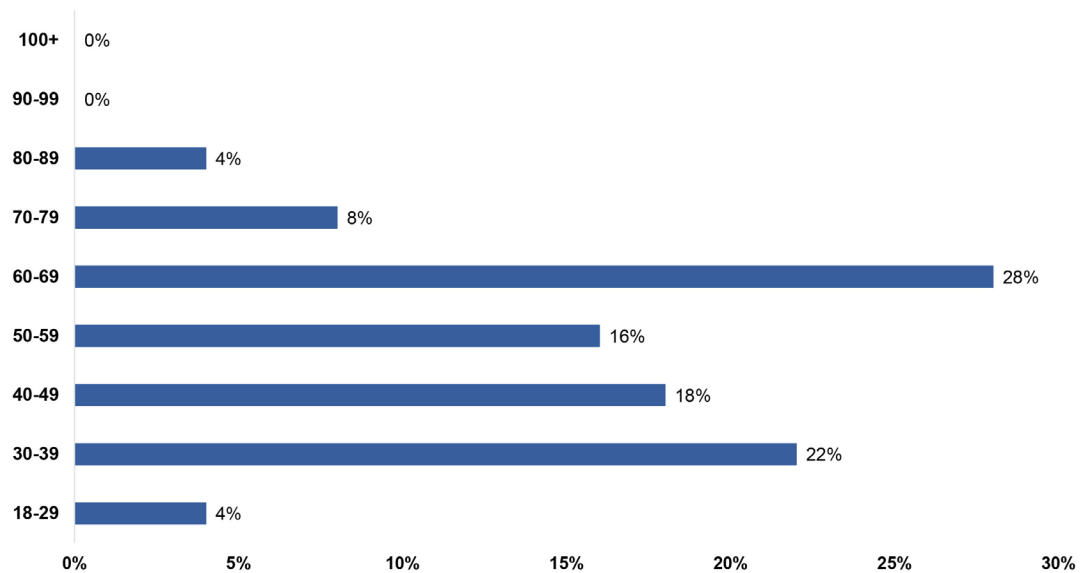
The Centre on Aging conducted a study of COVID-19 vaccination decision-making in personal care homes (PCH) in Manitoba. This research project focused on residents who were not able to make their own decisions about being vaccinated, and the aim of this study was to learn more about the perspectives and experiences of employees, volunteers, and families and friends of residents regarding vaccination decision-making specifically related to the COVID-19 pandemic. Eligible participants had to be 18 years of age or older, someone who either worked or volunteered at a PCH during the pandemic, and/or a family member or friend of a PCH resident in Manitoba during the pandemic who was not able to provide their own consent to be vaccinated against COVID-19.

The first three questions of the survey were asked to all participants, while the remaining questions were asked based on the respondent's role: family/friend or staff/volunteer. A total of 98 individuals responded to the surveys overall. Of these, 11 were removed from analysis for the following reasons: five were neither family/friend nor staff/volunteer; four provided consent only and then withdrew from the survey; and two did not provide consent to use partial data and then withdrew from the survey. As a result, 54 individuals responded to the family/friend survey and 33 completed the staff/volunteer survey. Furthermore, not everyone answered every question.

Family/friend survey demographics

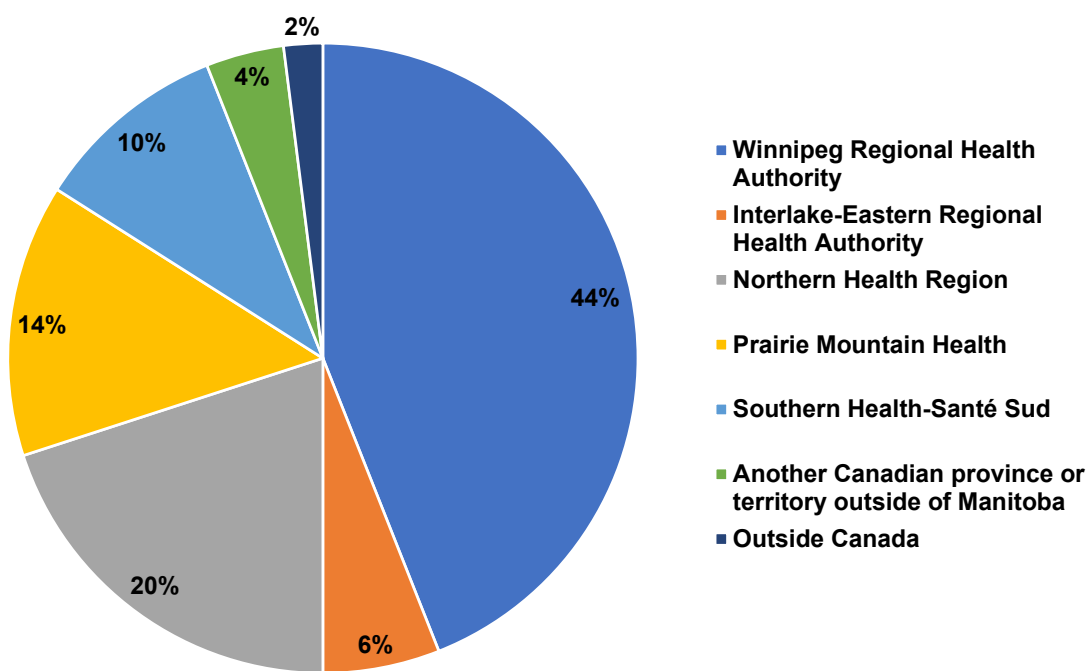
A total of 25 questions (including 3 demographic questions) were asked in the family/friend survey. Thirty-three (66%) respondents were women, 16 were men (32%), and the rest either preferred not to answer or skipped the question. There was a wide age range with many respondents in the 60–69 age group (28%) followed by those in the 30–39 age group (22%; Figure 1).

Figure 1: Age distribution among respondents.



The respondents were from different health regions of Manitoba, with the most being located in the Winnipeg Regional Health Authority (44%) followed by the Northern Health Region (10%; Figure 2). When asked about their loved one’s PCH location, 51% selected Winnipeg Regional Health Authority, 21% selected Interlake-Eastern Regional Health Authority, 15% selected Northern Health Region, 13% selected Prairie Mountain Health, and no one selected Southern Health Santé Sud.

Figure 2: Respondent distribution among the health regions of Manitoba and outside Manitoba.



When asked about their loved one’s PCH location, 51% selected Winnipeg Regional Health Authority, 21% selected Interlake-Eastern Regional Health Authority, 15% selected Northern Health Region, 13% selected Prairie Mountain Health, and no one selected Southern Health Santé Sud.

When asked about their relationship with the resident living in the PCH, most were daughters (35%), 15% were sons, 11% were wives, and 11% were daughters-in-law. The remaining respondent relationships with residents are listed in Table 1.

Table 1: Respondents' relationship to the resident.

Relationship	Responses # (%)
Daughter	19 (35%)
Son	8 (15%)
Daughter-in-law	6 (11%)
Wife	6 (11%)
Son-in-law	4 (7%)
Friend	4 (7%)
Husband	3 (6%)
Brother	1 (2%)
Sister	1 (2%)
Niece	1 (2%)
Grandchild	1 (2%)
Nephew	0 (0%)
Other	0 (0%)
Total	54

Vaccination decision-making involvement

Respondents were asked if they had been officially responsible for making a COVID-19 vaccination decision on behalf of any resident residing in a PCH. A total of 54 participants responded to the question, with 93% saying yes.

Out of the four individuals who were not responsible for making a COVID-19 vaccination decision on behalf of a resident, two (50%) however indicated they had involvement in the resident's vaccination decision. When further asked how they were involved in the vaccination decision-making process, they both indicated they had conversations with the decision-maker, and one also looked

up information regarding vaccination on behalf of the resident or their decision maker. One respondent agreed with the ultimate decision that was made by the resident or their official decision-maker for the resident to be vaccinated or not. The other respondent did not respond to the question. Respondents were asked for the reasons for their selection. One respondent felt that their opinion was not relevant and that vaccinations were “imposed” on residents, whereas another respondent trusted that those responsible for making the decision would make the “right decision”.

When respondents were asked for their official title related to making decisions for a resident who lives in a PCH, most of the respondents (51%) identified themselves as power of attorney, 39% selected primary or alternative decision-maker, and 31% chose designated caregiver. The remaining titles are listed in Table 2 (note that multiple options could be selected). Those who said ‘other’ replied, “As next of kin of my husband, I am consulted on all decisions.”

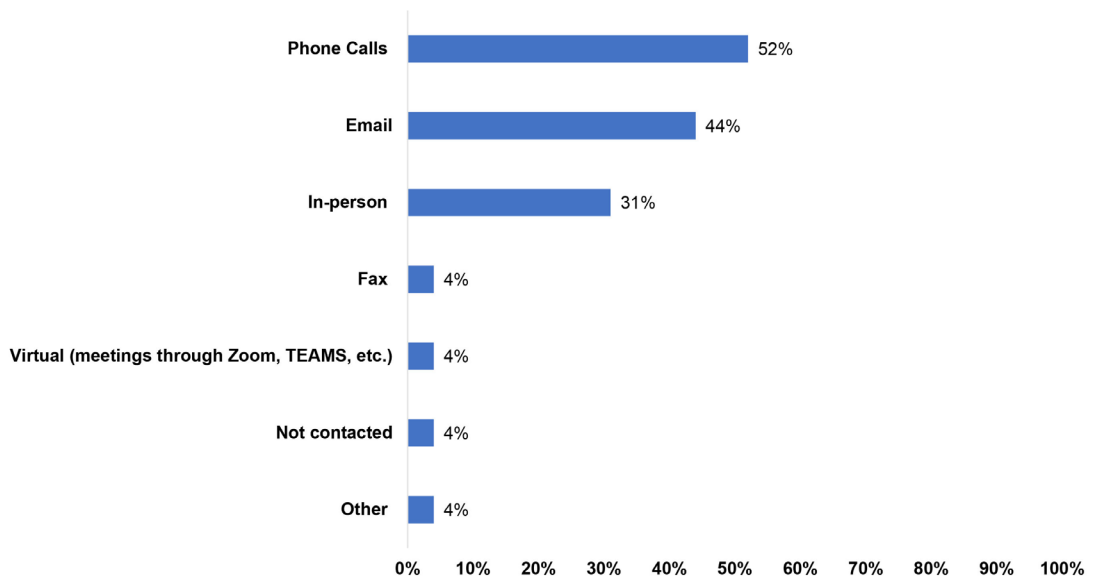
Table 2: Respondents’ titles related to making decisions for a resident.

Official title	Responses # (%)
Power of attorney	25 (51%)
Primary or alternate decision-maker	19 (39%)
Designate caregiver	15 (31%)
Proxy for healthcare directives	14 (29%)
Legal representative	10 (20%)
Next of kin	10 (20%)
I don’t know	2 (4%)
Other	1 (2%)
Total respondents	49

Consent process

When asked how the PCH contacted the decision-makers regarding providing consent for the COVID-19 vaccination for residents, 52% received phone calls, 44% were contacted via email, 31% were contacted in person, and the rest of the respondents selected fax, virtual, not contacted, or other (Figure 3; multiple options could be selected). One respondent in the 'other' category indicated that they were next of kin but not power of attorney and were not contacted for their consent, although the individual with the power of attorney contacted them for their opinion.

Figure 3: Ways respondents were contacted by PCH for their consent.



Decision-making process

The majority of respondents (67%) indicated involving other individuals in making their decision regarding the vaccination of the PCH resident. As noted in Table 3, when respondents were asked who they involved in the decision-making process for the resident, 39% selected a family member of the resident, 33% said that they involved the resident, and another 33% indicated staff at the PCH. Respondents could select as many individuals as applied. Other responses are in Table 3.

Table 3: Individual involved in the decision-making process for the resident.

Individual involved	Responses # (%)
Family members of the resident	13 (39%)
The resident	11 (33%)
Staff at the PCH	11 (33%)
Healthcare professionals not at the PCH	10 (30%)
Friends	4 (12%)
Other	0 (0%)
Total respondents	33

Most respondents (98%) indicated that they provided consent on behalf of the resident for the COVID-19 vaccination. Only one respondent did not provide consent for religious reasons and disagreement between decision-makers. They indicated they were required to provide documentation to the PCH for not providing their consent for vaccination.

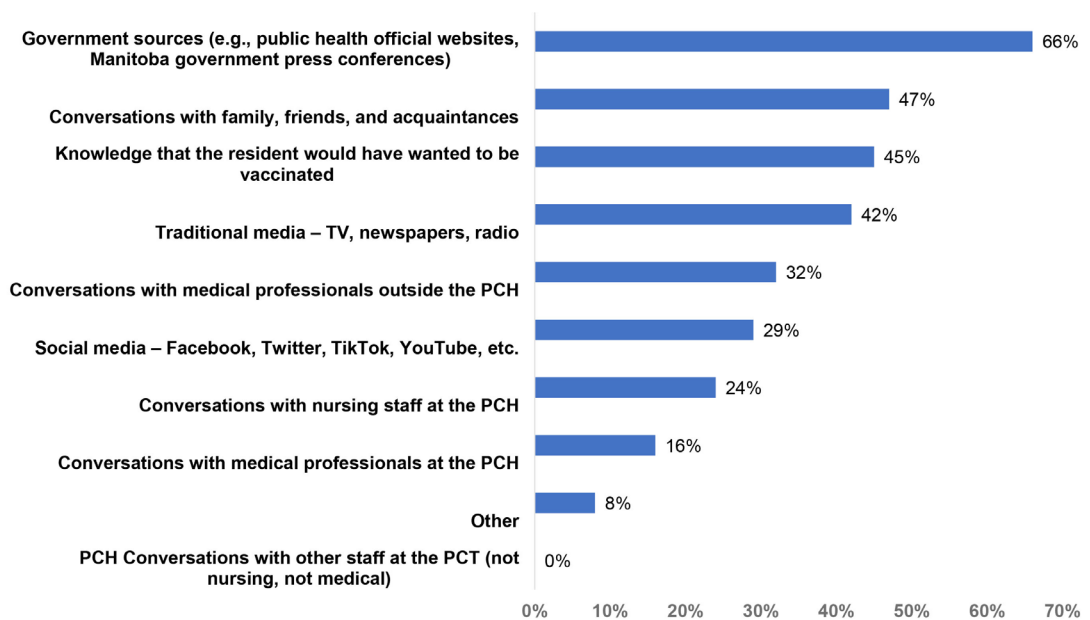
Influenza vaccination

When asked if their resident had typically received a flu shot in the past, 84% of the respondents selected yes, 6% selected no, and 10% were unsure. Respondents were also asked during the COVID-19 vaccination decision-making process if they had followed a similar thinking process as they had for yearly influenza (flu) shots. In response, 88% of respondents selected yes, 10% selected no, and 2% selected that they were unsure.

Sources of information on COVID-19 vaccination

Most of the respondents (78%) said they used external sources of information other than what was sent to them by the PCH to make their COVID-19 vaccination consent decision. The majority of respondents (66%) used government sources, while 47% indicated conversations with family, friends, and acquaintances, and 45% considered the knowledge that the resident would have wanted to be vaccinated (Figure 4; multiple options could be selected). About 42% of respondents selected traditional media (TV, newspapers, radio), while 29% selected social media (Facebook, Twitter, TikTok, YouTube, etc.). All responses are listed in Figure 4.

Figure 4: Sources of information that respondents used in making their decision regarding COVID-19 vaccination.



Family conflicts

Most of the respondents (60%) did not have any family conflicts arise surrounding the vaccination of the PCH resident, however, a sizable number did (40%).

Although those respondents who indicated that there were family conflicts were asked to describe the conflict and how it was resolved (if it was resolved), the responses were unclear or missing.

Perspectives over time

When asked if their thinking about COVID-19 vaccines for PCH residents changed from the beginning of the pandemic to now, 64% said no. In the comment section, respondents were asked to explain, and example responses are included below.

- “I’ve had the two shots. I will not get more.”
- “They diagnosed my loved one with liver cancer just before the next vaccination clinic. I was concerned either (as given at the same time) would create side effects unrealized before.”

Conclusions

In summary, there were wide-ranging findings from families and friends of residents regarding vaccination decision-making, specifically related to the COVID-19 pandemic. Respondents came from all health regions in Manitoba as well as outside Manitoba and Canada. Residents were from all the health regions in Manitoba except the Southern Health Santé Sud region. Most of the respondents indicated that they had been responsible for making a COVID-19 vaccination decision on behalf of a resident living in a PCH. Many respondents to this survey identified themselves as having ‘power of attorney’ when asked about their official title in the vaccination process. During the vaccination decision-making process, most of the family or friend decision-makers were contacted either by phone or email for their consent. Other individuals involved in the decision-making process included family members of the resident, the resident themselves, and staff at the PHC. Nearly all (98%) survey respondents said they provided consent on behalf of the resident for the COVID-19 vaccination. Most respondents indicated their resident typically received the flu shot and that they had followed a similar thinking process when making a decision about the COVID-19 vaccination. Respondents used a variety of external sources of information in making their decision and included government sources, conversations with family, friends, and acquaintances, and knowledge that the resident would have wanted to be vaccinated, in addition to the information sent by the PCH to make their decision about the COVID-19 vaccination. About 40% of respondents had family conflicts surrounding the decision-making process. While negative thinking about the COVID-19 vaccines was expressed by a minority of respondents, overall, most of those who responded to the family/friend survey were supportive and gave their consent for vaccination.



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