

# Recommendations for health care directives regarding vaccinations

Summary of findings



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In the fall of 2023 and winter of 2024, two online surveys were used to gain input on health care directives for vaccinations in Manitoba. In the first survey we asked questions about the general concept of health care directives and vaccinations, and proposed a few statements that could be used by individuals. We asked survey respondents to rate these statements and provide their specific comments and suggested revisions.

Based on the feedback from the first survey, we proposed one statement, and then asked for further input, suggestions, and comments. This report provides a general summary of the findings from both surveys.

By way of background, as described by Manitoba Health, health care directives in Manitoba allow individuals to:

“express [their] wishes about the amount and type of health care and treatment [they] want to receive should [they] become unable to speak or otherwise communicate this [themselves]. It also allows [them] to give another person the power to make medical decisions for [them] should [they] ever be unable to make them [themselves].”

In addition to providing information, the Manitoba Health [website](#) on health care directives provides a sample form that could be used to outline an individual’s medical treatment wishes (or “instructions”), as well as to identify a person or persons called a “proxy” who would make treatment decisions for the individual in the event they were unable to do so on their own.

There are a variety of circumstances that might require health care directives to be used (e.g., accident, illness, cognitive impairment). For example, when an individual - regardless of whether they live in the community or in a long-term care facility (e.g., personal care homes (PCHs)) - has a cognitive impairment that does not allow them to make medical treatment decisions themselves, another person, such as a substitute or alternate decision-maker would be consulted to provide consent. This includes scenarios where consent is needed for a vaccination.

In some cases, a person will have created a health care directive and have specifically named a proxy within that directive to make treatment decisions on their behalf. However, in many cases, substitute decision-makers, including named proxies, do not always know what treatment an individual might have chosen for themselves.

## Survey #1, Fall 2023

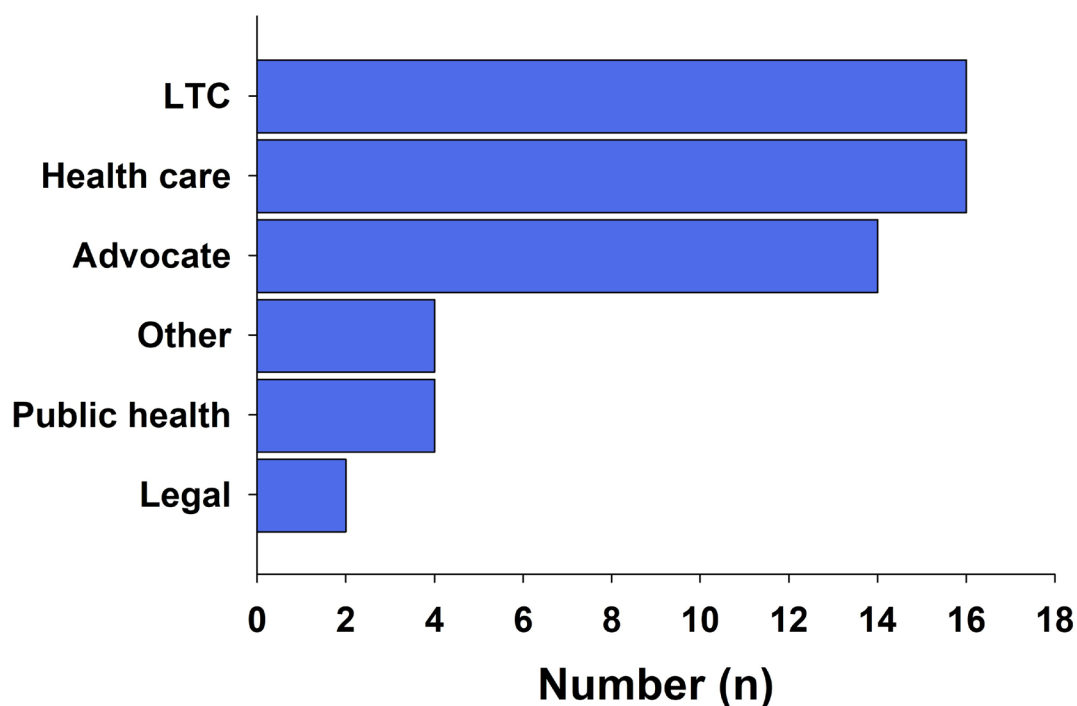
To ensure that an individual's wishes regarding vaccinations are known, we have proposed some statements that an individual could include in their health care directive. In this study, we consulted with individuals who have knowledge about health care directives based on the setting in which they work (e.g., health care, long-term care, legal, advocacy for older people). Those who volunteered completed an online survey with 31 questions which took about 20 minutes to complete.

## Participants

In total, 39 participants completed at least some of the questions from the survey. All 39 participants indicated that they work or advocate primarily in the Winnipeg Regional Health Authority. Of the 33 who responded to the question about their gender, 19 answered 'Woman', 3 'Man', and 1 'Non-binary/Trans/Gender'. Age groups of respondents ranged from '18–29' to '70–79', with more than half of participants choosing the '40–49' or '50–59' age ranges.

A variety of fields were reported with many indicating advocacy, acute health care, long-term care (see Figure 1 on page 3; note that more than one category could have been chosen by each person). Only two participants indicated that they represented the legal profession. Eight participants chose 'Other' and then indicated the following fields: "Public Health" (4 individuals); "MD working with seniors in multiple settings"; "working in MB Housing building with older adults"; "concerned citizen"; and "professional working with older adults in the community, former LTC worker".

**Figure 1: Fields of the participants (note: they could choose more than one category). LTC = long-term care.**



## Health care directives for vaccinations

The first question about health care directives asked participants whether they think “it makes sense in Manitoba for individuals to make health care directives that are specific to vaccinations.” The vast majority (87.2%) indicated ‘Yes’. The participants had the opportunity to provide a comment after this question. Thirteen individuals commented. The topics of those comments included: logistical challenges/administrative challenges/confusion for individuals making directives; being proactive is valuable; sample statements could be provided; include on existing forms; doubts about consenting to future treatments; and that this would alleviate situations where family members having opposing opinions or decide not to vaccinate when there is “zero evidence of a strong belief by the Resident to not be vaccinated”. Finally, one participant suggested that the “default should be to vaccinate in any long-term care facility”.

## Context for vaccination decision-making process

Next, participants were asked: “Do you have any context to add to the vaccination decision-making process for adults who are not able to make that decision themselves?” Responses to this question included the following topics: a clear directive would decrease confusion/resistance for Public Trustee; importance of health directives should be better emphasized with education and advertisements; decision-makers need to honour the wishes of the individual and not provide/decline consent based on their own thoughts; vaccination is critical for long-term care to protect everyone living there; disinformation/misinformation regarding vaccinations is a “huge issue”; and vaccination status also has “social implications such as isolation or prevention of certain “privileges”.”

## Recommended statements

Participants were next asked questions about vaccination-specific recommended statements that could be added as part of a health care directive, as proposed by the researchers. Questions included:

Was the statement clear?

Would they suggest that any words be added or removed?

Overall, most participants ‘agreed’ or ‘strongly agreed’ that the statements were clear (see Table 1 on the next page for the statements and the ratings regarding clarity).

**Table 1: Frequency (%) of level of agreement ('Strongly agree' to 'Strongly disagree') for whether the statement was clear (n=39).  
No one chose "strongly disagree" for any of the statements.**

Statement	Strongly agree	Agree	Neither agree nor disagree	Disagree
"I wish to receive any vaccination that is being recommended for those living in long-term care settings by Manitoba Health and/or the National Advisory Committee on Immunizations."	51.3	38.5	5.1	5.1
"I wish to receive any vaccination that is being recommended for individuals who are 65 and older by Manitoba Health and/or the National Advisory Committee on Immunizations."	48.7	46.2	2.6	2.6
"I wish to receive any vaccination that is being recommended for adults by Manitoba Health and/or the National Advisory Committee on Immunizations."	51.3	38.5	2.6	7.7

Several suggestions were made for revisions to each of the statements, with similar edits being suggested for all three statements. Notable suggested edits are shown in Table 2 on page 6.

**Table 2: Notable suggestions were given regarding edits for the statements above.**

**Suggested edit**

Add “Free” vaccinations

Add something about contraindications or “my specific situation”

“Remove specific reference to long term care”

Change “wish” to “consent”

Remove “any”

Remove reference to “National Advisory Committee on Immunizations”

Change to “all vaccinations..”

Remove “Manitoba Health”

Add specific types of vaccines

Add something about “those vaccines that I am eligible for”

Add “Provided the benefits of the vaccine outweigh the risks as assessed by my current medical practitioner.”

Concerns were expressed about using an age like 65 and older

I would say “adults/older adults”

When asked to rank the statements in order of preference, 32 individuals responded. The statement regarding “adults” received the most #1 responses (n=12, 37.5%), and both other statements (65+ and long-term care) received ten #1 responses.



## **Possible negative consequences and practical implications regarding health care directives related to vaccines**

Participants were asked whether they “foresee any negative consequences of promoting health care directives related to vaccinations” and to provide specific comments. Thirty participants provided responses to this question, with 11 participants indicating they did not think there would be negative consequences. For the 18 participants who thought there would be or possibly could be negative consequences, many expressed that the anti-vaccination sentiments of decision-makers and the possibility that these decision-makers would still “overrule” a specific health care directive was a major issue. A few other participants brought up the possibility of there being family disagreements, and that an additional item in a directive could make the health care directive process more overwhelming.

## **Practical implications of health care directives for vaccinations**

Participants were asked to provide their input on what practical implications would need to be considered regarding health care directives for vaccinations in their setting or profession. Table 3 on page 8 shows the various categories of implications brought forward by 25 participants (note: some implications were given multiple times by different participants, and participants might have listed multiple implications).

**Table 3: Practical implications to be considered regarding health care directives for vaccinations.**

### **Practical implications**

Logistical issues will need to be overcome with either adding directives to an existing form or with the creation of a new form

Challenges with discussing specific situations far in advance of people needing them and the fact that they can change their mind

Administrative burden

Possibility of having standard medical order protocols rather than needed specific orders for each specific vaccine

Sufficient education so conversations can be informed

Competence of individuals

Access to health care directives is challenging for all those who might need access - better to have this as part of an electronic record

Ensuring that individual's wishes were honoured and that someone does not overrule their directive

Try to ensure that this is done before admission to a PCH

Accessibility to vaccines can be challenging

Education with professionals "regarding the legal and ethical implications of upholding a health care directive"

Physicians and others might still want the decision-maker to provide consent despite what is written in directive (this happens sometimes in hospitals with advanced care decisions)

Try to ensure that family members are made aware of the individual's intentions

### **Other comments**

Other comments by participants in various places in the survey suggested that there should be options within the directive to indicate that specific vaccines should not be given in certain situations (e.g., when an individual is receiving palliative care), or not at all.

## **Groups for education regarding vaccination-specific health care directives**

Finally, we asked participants about who should be engaged in educational efforts regarding vaccination-specific health care directives. There was broad support for all the groups that were suggested in the survey: public including older adults; organizations that already provide education regarding health care directives; legal professionals; health care professionals; PCHs; and the provincial government. In addition, a few participants provided some additional ideas regarding this topic. This included ideas in relation to “informing even young adults (in the school system),” media, as well as professional and educational organizations (Colleges for nurses and physicians).

## **Conclusions and next steps**

The findings of this initial survey were highly informative in terms of real-world use of health care directives and how vaccination-specific directives or instructions might work. The next phase of the project sought input on one statement we crafted based on the feedback summarized above, and similar questions on practicalities.

## Survey #2, Winter 2024

Based on the initial feedback we received in survey #1, we proposed the following statement for further input on a second online survey:

“I **consent** to receive **all medically indicated** vaccinations that are being recommended for **adults/older adults** (e.g., by Manitoba Health and/or the National Advisory Committee on Immunizations).” [words in red indicate changes from survey #1]

We also explained that further information would be provided with this suggested statement to indicate that this statement could be added to the Manitoba health care directive form for those who want it, to explain what “medically indicated” means, and that someone could indicate whether they want to receive vaccines that are not covered by Manitoba Health and hence require payment.

## Participants

Participants for this survey did not have to complete Survey #1, but they might have. Because the surveys were anonymous, we are not able to indicate how many individuals might have completed both surveys. Our invitation email for Survey #2 seems to have reached a much larger and varied audience compared to Survey #1, with more details provided below.

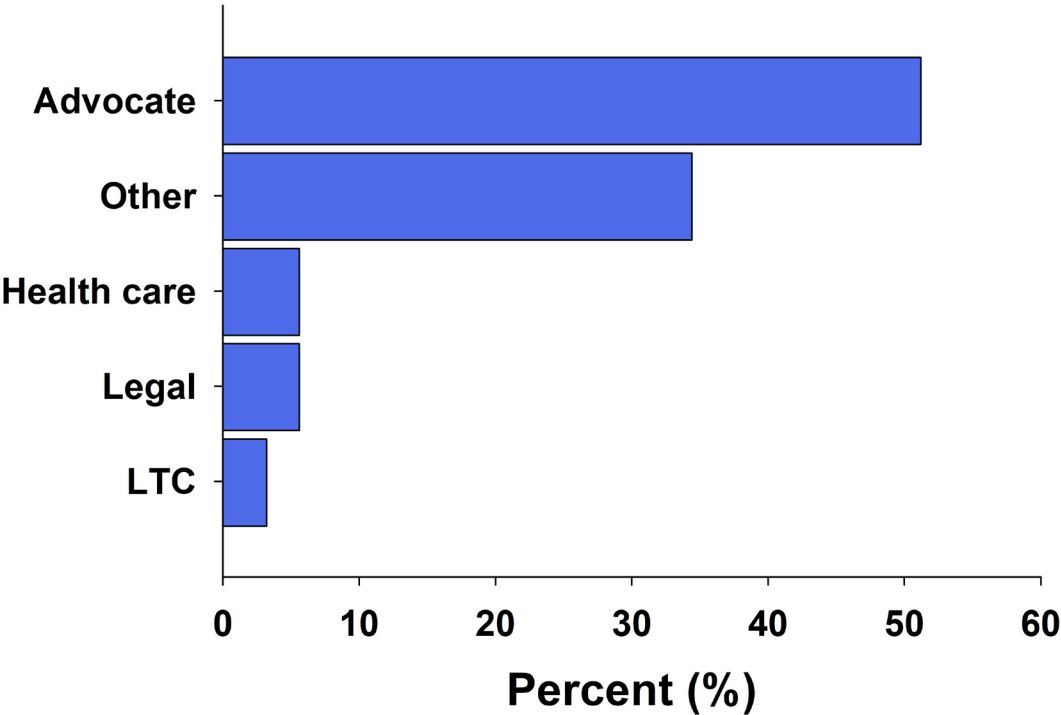
In total, 151 participants responded to at least some of the questions on the second survey. All health regions were represented with at least one response, for those who responded to this question (n=113), with 60.2% from the Winnipeg Regional Health Authority, 14.2% from Prairie Mountain Health, and Interlake-Eastern Regional Health Authority and Southern Health-Sante Sud each had 12.4%. Only one participant indicated that they were from the Northern Health Region.

About two thirds of participants responding to the question about gender (n=116) were women (65.5%), the rest indicated they were men. Age groups ranged from

30 to 39 years up to 80 or older, with more than two thirds being in the 60 to 79 age brackets.

A large number of participants (n=64) indicated that they are an advocate for older adults, with a smaller number indicating that they are professionals working in the following settings: acute health care (n=7); long-term care (4); and legal (n=7) (See Figure 2 below). Further, many participants identified as 'Other' (n=43). Descriptors given by these participants included: older person or individual (n= 19); retired from healthcare (n=6); volunteer (n=5); involved with senior centres or boards (n=2); social worker in community based care (n=1); public health (n=1); resource coordinator (n=1); support worker (n=1); non-governmental organization (n=1); rancher (n=1), minister (n=1); and a few additional participants did not indicate a specific group.

**Figure 2: Fields of the participants. LTC = long-term care.**



## Recommended statement

When presented with the recommended vaccination-specific health care directive, participants were asked “Is this statement clear?”. Most (83.3%) either strongly agreed (42.0%) or agreed (41.3%). A further 6.0% neither agreed or disagreed, 6.7% disagreed, and 4.0% strongly disagreed.

Open-ended comments after this question indicated that there were a variety of responses expressed from those who were very positive about the statement to those who conveyed negative sentiments in general about vaccinations. Several participants provided comments regarding the phrase “medically indicated” and its clarity. Many others made comments about vaccines that were not covered by the provincial health system. Quite a few participants commented on allergies and vaccines. Some participants made suggestions about possible additions to the directive (timing for updates, opting in for select vaccines, examples of medically indicated vaccinations). One person expressed the hope that perhaps this would eliminate the need for so many consents “once incapacitated”. Finally, one participant thought the inclusion of “e.g.” before the authorities listed in the statement (National Advisory Committee on Immunizations and Manitoba Health) might mean that the statement could be interpreted as including anyone’s recommendation such as a neighbour.

Participants were next asked to answer ‘Yes’ or ‘No’ as to whether they felt that the statement would be effective (i.e., if a person included this statement in their health care directive, would that person receive all medically indicated vaccines in the event they could not consent for themselves sometime in the future, regardless of where they lived or how they receive their health care?). Of the 118 participants who answered this question, more than two thirds (72.0%) indicated ‘Yes’. When asked “Why or why not?”, participants provided a variety of responses, some of which included points similar to those mentioned in relation to the clarity of the statement as described above. Additional points questioning the effectiveness of the statement are shown in Table 4.

**Table 4: Points regarding the effectiveness of adding the statement to a health care directive.**

**Points regarding effectiveness of a vaccination health care directive**

Issues with the lack of clarity with the form itself

Consent still being needed by the health care proxy and they might make a different decision

Whether a health care directive could be used as “part of a normal health care plan” rather than during a crisis

Would the health care directive be accessible or known about?

A lawyer could “twist the situation to cast doubt on what the statement clearly implies”

There was also lack of confidence in the health care system expressed by a couple of individuals in terms of reading “a whole chart” or ensuring that someone in a care home would get vaccinated

“If a person no longer has the capability to consent on their own, then why are we trying to prolong life”

The next open-ended question asked participants how they would revise the provided statement. Participant suggestions are shown in Table 5 on page 14.

**Table 5: Suggestions were given regarding edits for the statements above.**

<b>Suggested edit</b>
Add the word “tested” regarding vaccinations
Include definitions of terms
Add statements specific to the proxy providing consent on their behalf
Include timing of immunizations
Make the provincial authority more generic
Allow for exceptions to be listed
Stipulate that I only want to be vaccinated if I am relatively healthy and “still have some quality of life”
Make mention of the future explicit
Use “medically directed vaccinations” instead of “medically indicated vaccinations”
Possible negative consequences of health care directives related to vaccines

Like Survey #1, participants were asked about whether they could foresee any possible negative consequences of promoting this vaccination-specific statement for inclusion in a health care directive. Almost half of participants who responded to this question indicated that they could not foresee possible negative consequences. However, there were others who thought of possible negative consequences or simply answered “Yes”. Several of these participants gave answers related to specific medical situations and possible effects for individuals (e.g., changes in health status, allergies), rather than general broader negative consequences. One participant provided examples of how many health care professionals have limited understanding of the provincial legislation that governs health care directives and therefore might proceed incorrectly if a vaccination-specific statement was included. Another participant further suggested that “It could erode the idea of “informed consent” in the public discourse.”



## Education related to health care directives for vaccinations

Participants were asked: What kinds of questions or issues would need to be addressed in any educational materials created to accompany the recommended statement? Participants were able to provide multiple examples and for different audiences. It was suggested by some that there needs to be more education about vaccines (including in relation to: benefits for individuals, others, and society; risks of not being vaccinated; side effects; which ones are recommended for specific age groups; does it need to be updated, etc.). In general, participants suggested that education on health care directives in many settings and for different groups (e.g., health care) is needed. Participants also suggested it might be best to give example scenarios of what such a health care directive would mean for the future of the maker of the directive. Within health care, one participant recommended charting education.

## Other comments

Finally, participants were asked to provide any other comments regarding health care directives for vaccines. One person suggested “Rather than adding the statement to Part 2 of the provincial form, maybe consider including it in an information circular, together with containing other . . . considered treatment instructions (such as do not resuscitate, no heroic measures, no force feeding).” Another participant commented that where the directive is stored may also need to be considered. Some participants did not see the value of this kind of health care directive because they were more familiar with directives that limited care received, particularly in palliative situations.

## Conclusions

The results of both surveys will be very useful in providing recommendations regarding health care directives and the possibility of including specific statements or instructions regarding vaccination. These recommendations could also include a range of educational directions for a variety of different audiences in the province of Manitoba.



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