

Ontario Vaccine Deliberation Report



DISCOURSE, SCIENCE, PUBLICS
UNIVERSITY OF GUELPH

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Acknowledgements: We gratefully acknowledge funding support from the Canadian Institutes for Health Research (CIHR). The authors also gratefully acknowledge the helpful input of Wade Pickren, Timothy Caulfield, Mike Pettit, & the Discourse, Science, Public Research Group at the University of Guelph.

April 2018
Guelph, Ontario, Canada



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Table of Contents

Executive Summary	4
Introduction to the Ontario Vaccine Deliberation.....	6
Purpose and Goals.....	6
Why Focus on Vaccines?	7
The Principles of Public Deliberation	8
Methods.....	9
Participant Selection	9
Existing Knowledge and Pre-Deliberation Activities	9
Ontario Vaccine Deliberation Process	10
Deliberation Questions	13
Recommendations	14
Mandatory Vaccination and Exemptions.....	15
Communication about vaccines and vaccination.....	20
AEFI Compensation and Reporting	22
Conclusions.....	25

Executive Summary

In October 2017, a public deliberation was held to address the issue of childhood vaccinations in Ontario. This report describes the purpose, methods, and outputs (recommendations) of the Ontario Vaccine Deliberation public engagement event.

Childhood vaccination is a topic characterized by strong polarization of opinion. Although there is compelling scientific evidence for the efficacy and safety of vaccines, and the majority of Canadians is strongly supportive of vaccination, a small minority of Canadians is opposed to childhood vaccination. In addition, there is a substantial and growing proportion of Canadians that is uncertain or hesitant about vaccination. The success of public health efforts to decrease resistance and hesitancy toward childhood vaccination through promotion of and education about childhood vaccination has been limited. The purpose of the Ontario Vaccine Deliberation was to provide an opportunity for a diverse public to provide input for vaccine policy, given the range and polarization of views on the topic. Although participants were informed about current policy in Ontario, they were asked to discuss the topic independent of consideration of the current policy context. The key questions considered by the public forum were:

1. How should vaccine policy respect parents' responsibilities to their children while reducing risk to other people?
2. Should certain childhood vaccinations be required in Ontario?
3. How should information about vaccination and vaccination policy be communicated?
4. What are appropriate responses when an adverse event related to a vaccination is reported?

Public deliberation is a process in which a group of (typically lay) citizens or residents of a particular region come together to discuss an issue¹. Twenty-five participants were selected for diversity from across Ontario to take part in 4 days of in-depth deliberation about childhood vaccination. To prepare for the deliberation, participants received an accessibly written information booklet and heard presentations from 5 speakers with diverse areas of expertise and perspectives. Participants then deliberated about the key questions in both small (5-6 participants) and large groups (all 25 participants) with the help of trained facilitators.

The process of deliberation involved:

- Respectful engagement at all times.
- Careful consideration of everyone's perspectives.
- Offering opinions on the topic backed up by reasoning.
- Willingness to change one's opinion based on new information or hearing the arguments and perspectives of others.
- Collectively working toward recommendations for policy that were as inclusive as possible of the different views that were proposed during the course of the deliberation.

Participants developed a total of 20 recommendations. Each of these recommendations was voted on to help the facilitator identify and document the reasoning of both those in support of the recommendation and those against it. Key conclusions of the participants in the Ontario Vaccine Deliberation include:

- Strong support for mandatory childhood vaccination in Ontario.
- Recognition of the difficulties associated with defining ‘mandatory’ in this context and how vaccination requirements should be enforced.
- Strong support for communicating about vaccination through multiple channels, including the possibility of including information at events such as health card renewal notifications. In addition:
 - Providing information about childhood vaccination to parents and prospective parents specifically during pregnancy and after birth.
 - Providing education about vaccination through the school curriculum.
 - Information provided about vaccination should be scientific and unbiased, addressing the risks, benefits, and concerns of childhood vaccination.
 - Alternative communication mechanisms, such as social media, should be considered.
- Strong support for the establishment of a provincial or national compensation scheme for adverse events following immunization (AEFI).
- Strong support for tracking AEFIs for purposes of ensuring vaccine safety.
- Strong support for mandatory reporting of AEFI by health professionals to Public Health Units.

Issues that were discussed and which were subject to persistent disagreement even after intense deliberation:

- Whether exemptions should be allowed for religious reasons.
- Whether exemptions should be allowed on grounds of conscience or personal beliefs.
- The consequences for individuals who do not have their children vaccinated without valid exemptions.

Introduction to the Ontario Vaccine Deliberation

Purpose and Goals

The Ontario Vaccine Deliberation was a **public deliberation** event held in Waterloo, Ontario, over 4 days on October 14, 15, 28 and 29, 2017. The project was hosted and organized by a research team from the University of Guelph, and supported by a grant from the Canadian Institutes of Health Research (Principal Investigator, Dr. Kieran O'Doherty). Public deliberation events are informed by political theory on deliberative democracy and are based on the idea that it is important to have wide citizen input about decisions on issues that affect us all, particularly for issues that are considered controversial. The purpose of public deliberations is not to convince participants of any given position on the issues being discussed, but rather for participants to deliberate among themselves to achieve collective positions that reflect the breadth of perspectives they bring to the discussion.

Public Deliberation

A public deliberation is a community discussion about a particular topic that is based on the idea that members of the public should have a voice in the issues that affect them. Public deliberation is a democratic process that involves citizens, not just policy makers or experts, in important policy discussions. (learn more about the topic of the deliberation on page 8)

The Ontario Vaccine Deliberation was convened on the subject of childhood vaccination. In Canada, public health experts rely on vaccines to protect children from serious diseases^{2,3}. However, the topic of childhood vaccination has become increasingly polarized, and media and public discussions about childhood vaccination have become increasingly antagonistic. On the one hand, public health experts seek to achieve high rates of vaccination uptake with the aim of protecting individuals and the community as a whole from serious diseases. The vast

majority of parents follow this advice and vaccinate their children. On the other hand, some parents express concerns about the efficacy and safety of vaccines^{4,7}. Debates between these positions have been escalating in intensity.

In spite of the importance of the topic and the strong views some Canadians have about childhood vaccination (both for and against), there has been little opportunity for the Canadian public to engage in formal discussions about childhood vaccination. The purpose of the Ontario Vaccine Deliberation was to provide a forum for reasoned and civic discussion about these issues. The aim was not to advocate either for or against vaccination. Rather, our aim was to engage in dialogue with residents of Ontario to both educate and share points of view. Our intention was to bring together people from different backgrounds, with different opinions and life experiences, and encourage them to work together to develop public recommendations for policy on the issue of childhood vaccination.



Why Focus on Vaccines?

Vaccines have been described as one of the greatest achievements in combating infectious diseases and promoting human health. However, there have been recent outbreaks of infectious diseases previously thought to have been well controlled in several provinces. These outbreaks have been linked to un-vaccinated (i.e., children who do not receive any of the recommended vaccinations) and under-vaccinated (i.e., children who receive fewer than the recommended vaccinations) individuals and communities. See Figure 1 for vaccination rates in Ontario. While the number of parents who decline to have their children vaccinated at all is quite small (< 3%), there is a much larger percentage of parents (up to 35%) who are considered “vaccine hesitant” by researchers⁷, physicians, and public health officials – that is, while they still vaccinate their children, they report having concerns about vaccines and may choose to delay or modify the recommended vaccination schedule⁸. Canadian research on parental attitudes towards vaccines has highlighted safety concerns even among those parents largely supportive of immunization practices, as well as varying attitudes about the necessity of certain recommended vaccines⁴.

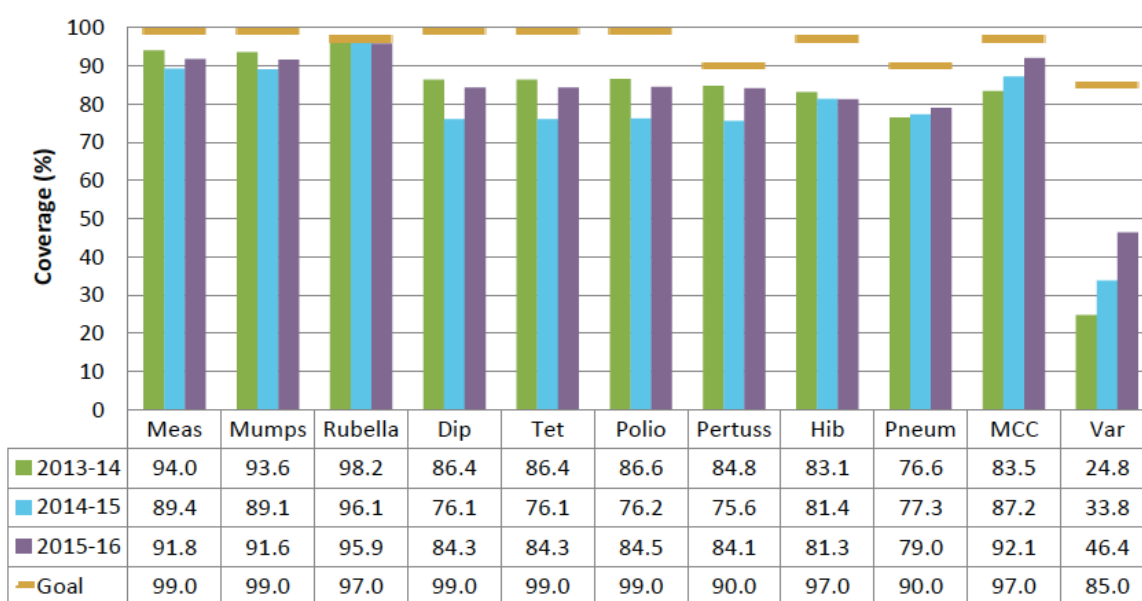


Figure 1. Up-to-date immunization coverage (%) in Ontario among children 7 years old: 2013-14, 2014-15, and 2015-16 school years (from *Public Health Ontario (2017) report, Immunization coverage report for school pupils in Ontario*⁹)

As a result of vaccination rates that are below national targets and recent outbreaks, public health agencies have attempted to encourage parents to vaccinate through educational materials about the science of vaccines and appropriate balancing of risks and benefits¹⁰. Research shows that educational campaigns on their own have not been completely successful because they cannot address important factors involved in parents’ vaccination decisions, including having alternative perspectives on health, being fearful of needles, religious beliefs inconsistent with vaccination, and mistrust in scientific expertise¹¹⁻¹⁵.

Childhood vaccination is a particularly divisive issue, in part because a small portion of the general public deems vaccines to be harmful, and individuals often take strong positions for or against vaccines. What is evident from observing interactions between different members of the public – including scientists, parents, and public health officials – on the topic of vaccines is that these exchanges are often polarized and heated. It is therefore challenging to engage on the topic of vaccines in respectful, open-minded dialogue that attempts to consider multiple perspectives. Having such opportunities for dialogue is critical, however, for the legitimacy of public policy aimed at protection of the public.

The Principles of Public Deliberation

Public deliberation is a democratic process that includes citizens, not just policy makers or experts, in important policy decisions¹. Public deliberation relies on the premise that as a society we need to find ways of living together according to commonly accepted norms and practices in spite of differences in opinion and values. Deliberative democratic events shift the discussion about important societal issues from telling people what they need to know about an issue to recognizing that individuals in society are sources of information and have important things to say about policy.

The purpose of public deliberation is to enhance the democratic legitimacy of societal programs, actions, and decisions. This is achieved by creating formal spaces for dialogue in which contested issues are discussed, taking into account available evidence and diverse perspectives on the topic. Public deliberation is particularly suited to facilitating dialogue when there are competing societal norms or values. The goal of conducting public deliberation on childhood vaccination was to enable reasoned debate. A key principle of public deliberation is to maintain a respectful environment so that all participants can speak freely.

Key Principles of Public Deliberation

- Maintain respectful environment so that everyone may speak freely by listening and engage in respectful discussion
- Be open to changing one's own opinion
- Provide reasoning/justification for one's own position
- Shift from working toward expressing individual opinions toward collective positions

Participants in a public deliberation are required to be respectful, listen to each other's perspectives, and be open (though not required) to changing their own opinions. When advancing their own perspectives, participants are required to provide reasoning for their position. Participants collectively weigh the advanced positions, consider their likely consequences and, ultimately, work toward collective policy recommendations¹⁶. During discussion, it is expected that individuals shift from expressing individual

opinions to working toward collective positions that ideally accommodate a range of different individual perspectives¹⁶. Although participants work towards consensus, clearly articulated persistent disagreements are valuable outcomes as this often allows for the development of deeper insights about underlying value conflicts.

Methods

Participant Selection

Twenty-five Ontarians over the age of 18 participated in the deliberation. Participants were selected to represent the diversity of residents in Ontario both in terms of demographics and opinions about vaccinesⁱ. A sample size of 25 is consistent with previous public deliberations¹⁷ and allowed for sufficient diversity across most demographic categories (gender, education level, occupation, parental status and age of children, attitudes towards vaccines) and enabled meaningful conversation. Nevertheless, there were limitations to the sample, with lower than desired representation of both younger and racialized participants.

To facilitate attendance, the deliberation was held on weekends with childcare facilities offered to participants who might need them and meals provided. Participants received \$100 per day of attendance. Participant recruitment and selection occurred in three phases.

Participant selection and recruitment process:

Phase 1: Invitation letters were sent to 5000 randomly selected households across Ontario. Individuals who were interested in participating completed a series of questions (online or by phone), relating to demographic information and attitudes towards childhood vaccines.

Phase 2: 30 participants were randomly selected from the pool of interested individual from Phase 1. As each person was randomly selected, their demographics were assessed and participants were replaced one by one until the sample of 30 selected participants was as diverse as possible.

Phase 3: The 30 participants who were selected from Phase 2 were emailed a selection notification and asked to accept or decline their participation. As participants declined, a new participant was selected from the pool who matched the invited participant demographically as closely as possible.

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ⁱ Despite efforts to ensure representation across ethno-racial and age groups through random sampling, the extent to which the sample is representative across all demographic categories is limited to the pool of potential participants that indicate interest in participating.

The Ontario Vaccine Deliberation Participants, Researchers, and Event Staff



Existing Knowledge and Pre-Deliberation Activities

Participants did not need to have prior knowledge about childhood vaccinations and were not expected to be experts on the topic. Participants were provided with information on the topic to ensure everyone had the same base of knowledge. Participants were encouraged to bring their opinions, values, and ideas about childhood vaccinations to the deliberation. They were informed that they would hear from expert speakers on the topic of childhood vaccinations and then work together as a deliberative cohort to make recommendations that could be used to more effectively inform policy decisions on childhood vaccinations.

Participants were provided with both paper and electronic copies of an information booklet¹⁸ two weeks prior to the event. They were asked to carefully read and consider the material and to bring questions and issues that arose for them to the deliberation.

“I really enjoyed the panel discussion, the Q and A session. I got to speak to [one of panelists] afterwards, at the dinner about her experiences...I thought that was insightful. I think the panel discussion ... probably had the most richness in it.” (Participant)

Ontario Vaccine Deliberation Process

The Ontario Vaccine Deliberation was held in Waterloo, Ontario. The deliberation was facilitated by a trained facilitator and was structured through plenary (large group) and small group break-out sessions to maximize available speaking time for participants.

Day 1 was focused on providing participants with information about childhood vaccinations and introducing them to the process of public deliberation. Information was provided by expert speakers who were chosen to reflect key societal positions and interests on childhood vaccination, as well as critical technical information. This included speakers on the topic of public health; complementary and alternative medicine (naturopathy); vaccine testing and safety; parental perspectives; and philosophical and historical approaches to vaccination. Participants were also told that they could ask for additional information on the topic, and the research team would seek this information out and present it to the group on subsequent daysⁱⁱ.

Day 2 and 3 were focused on deliberating the key deliberation questions (see page 13) as follows: discussing the issue, crafting statements that reflected collective positions, voting on each statement, and providing reasoning for each statement. More specifically, participants first discussed the issue(s) addressed in the question in their small groups of 5-8 fellow participants (randomly selected). Following small group discussions, participants convened as a large group to further discuss the issues identified in the small group discussions and work toward collective positions of the group. The points of discussion were formulated into preliminary statements by the facilitator and the group worked together to edit the statement until it represented a collective position. Next, participants individually voted on the statement(s) by indicating they were either *for* or *against* the statement. Participants could also choose to abstain from voting for a particular statement. When reasoning was not implicit in the statement, participants were asked to provide reasoning for their position.

Day 4 was focused on summarizing the group's recommendations and engaging in a ratification process to ensure all recommendations were captured accurately (see page 14 for additional information). This final ratification vote captured and took into account participants' changing perspectives on childhood vaccination as a result of the deliberation process. The Ontario Vaccine Deliberation concluded with a panel of experts who work in research, practice, and policy related to childhood vaccinations. This panel allowed for the experts to hear the recommendations produced by the group (who were present for the ratification vote) and for discussion between the experts and the participants.

“The most interesting thing to see yesterday was just the difference in types of discussions we were having where there was the start-off that we had the experts speaking to us, then there was the variety of them...and then we got the opportunity to be in a small group and then go to a bigger group...it allows for richer conversation to happen.” (Participant)

ⁱⁱ After 2 days of deliberation, the participants requested that the organizers of the event provide additional information to help them understand the positions of individuals and groups opposed to vaccination. In response, the research team identified several online videos from individuals and organizations opposed to vaccination, which were shown on Day 3 of the deliberation.

ONTARIO VACCINE DELIBERATION REPORT

See Appendix A for complete event schedule.

Session	Overview of Activities
Day 1	<ul style="list-style-type: none"> - Registration - Welcome and introductions large group session - Expert speaker presentations and panel <ul style="list-style-type: none"> - Speaker 1: Natasha Crowcroft, MD/PhD (<i>Public Health Perspectives on Childhood Vaccination</i>) - Speaker 2: Michelle Dreidger, PhD (<i>Parental Concerns about Childhood Vaccines</i>) - Speaker 3: Rick Olazabal, ND (<i>Advocating for Patient's Rights in the Age of Information and Confusion: The Other Side of the Coin</i>) - Speaker 4: Mina Tadrous, PharmD/PhD (<i>Pharmacovigilance and Vaccine Safety</i>) - Speaker 5: Jim Brown, PhD (<i>The Eradication of Smallpox</i>) - Hopes and Concerns small group session - Hopes and Concerns large group session
Day 2	<ul style="list-style-type: none"> - Overview of tasks and goals for Day 2 - Deliberation question 1 small and large group sessions - Deliberation question 2 small and large group sessions - Review and selection of questions for Day 4 - Evaluation
Two week period to reflect on discussions, seek additional information, and engage in discussion with family and friends about childhood vaccination.	
Day 3	<ul style="list-style-type: none"> - Deliberation question 3 small and large group sessions - Deliberation question 4 small and large group sessions
Day 4	<ul style="list-style-type: none"> - Deliberation question 5 small and large group sessions - Ratification of recommendations - Expert and policy panel <ul style="list-style-type: none"> - Panelist 1: Michelle Driedger, PhD, Professor, University of Manitoba - Panelist 2: Maya Goldenberg, PhD, Associate Professor, University of Guelph - Panelist 3: Jennifer Potter, MD, family physician - Panelist 4: Jacob Shelley, SJD, Assistant Professor, Western University - Panelist 5: Alison Thompson, PhD, Associate Professor, University of Toronto - Panelist 6: Frank Welsh, PhD, Director of Policy, Canadian Public Health Association - Participant evaluation of deliberation event

Deliberation Questions

The deliberation was structured around five questions, each with several sub-questions. These questions guided the small and large group discussions over the four days. Participants first deliberated on the questions in depth within their small groups and then worked toward collective positions as a large group on specific issues that arose from the small group discussions.

The first four questions were determined in advance of the deliberation by the research team. Participants had an opportunity to consider the questions as a group and suggest whether certain questions be changed or reworded to best capture the collective opinions of the deliberating groupⁱⁱⁱ. Participants also had an opportunity to identify important issues that arose during discussions, but were not adequately dealt with in the four previous questions. Participants selected three additional questions for discussion, grouped below as deliberation question 5.

See Appendix B for complete list of questions and sub-questions.

1. **How should vaccine policy respect parents' responsibilities to their children while reducing risk to other people?**
2. **Should certain childhood vaccinations be required in Ontario?**
3. **How should information about vaccination and vaccination policy be communicated?**
4. **What are appropriate responses when an adverse event related to a vaccination is reported?**
- 5A. **What exactly do we mean when we say vaccination should be mandatory?**
- 5B. **What restrictions on unvaccinated children are justified?**
- 5C. **How should we provide parents with all of the relevant vaccine information?**

ⁱⁱⁱ No changes to the questions were made

Recommendations

The Ontario Vaccine Deliberation resulted in 20 recommendations (or deliberative outputs), that reflect the collective decision making of the deliberants (participants). Deliberative outputs are explicit collective statements that arise from the deliberative process that convey a particular position or policy preference. In line with expectations for engagement in a deliberative process, participants changed their position about the issues being discussed throughout the four days of deliberation as they became aware of new information or were convinced by arguments made by their fellow participants. Collective positions were articulated when particular recommendations were voted on. There was an explicit opportunity for participants to change their individual position on a recommendation during the ratification phase of the deliberation, and a final opportunity to change their votes after the expert & policy panel on the last day of the deliberation. At that point, the collective positions were “locked in” and it is these deliberative outputs that are reported here. At no point did the organizers of the event or the facilitators of the discussions attempt to guide participants’ recommendations in any particular direction.

The deliberative outputs produced by the Ontario Vaccine Deliberation address three main areas:

1. Mandatory vaccination and exemptions
2. Communication about vaccine and vaccination
3. Adverse event following immunization (AEFI) reporting and compensation

Deliberative Output

“An explicit collective statement of deliberants about a position or policy preference” that is “recognizable by deliberants as the result of their deliberations” (O’Doherty, 2013, p. 7)

Not all of the recommendations had unanimous support of all participants. For each recommendation below, therefore, the number of deliberants who voted *for*, *against*, or *abstained* from voting is provided. These recommendations and corresponding vote counts are from the final ratification process on the final day of the Ontario Vaccine Deliberation.

Accompanying each recommendation and vote count is a summary of the reasons given by deliberants for their positions. In some instances, reasoning was implicit in the statement or prior discussion, and no additional reasoning was articulated by the participants; in these cases, no reasoning is provided for the recommendations. The number of votes supporting a recommendation does not necessarily indicate the degree of strength of the recommendation; rather, the vote allowed the facilitator to probe deeper into the reasons for and against particular positions.

Mandatory Vaccination and Exemptions

1. With certain exemptions, parents, legal guardians, and/or custodians have a responsibility to the health of the larger community through vaccinating all of their children

For	Against	Abstain
24	0	1

“Canadians have the responsibility to protect themselves and protect the society of Canada as a whole. And ultimately protect the individual by doing that.” (Participant)

Abstain
Unsure of position on vaccination.

2. Childhood vaccinations must be mandatory for all children in Ontario, with some exceptions.

For	Against	Abstain
25	0	0

For
Cons of vaccination do not outweigh the pros.
There is a reason why vaccination is done and we should follow.
Need to recognize the impact of diseases in the past without vaccination.

3. By mandatory, we mean children who are not vaccinated and without valid exemptions shall be excluded from school and organized activities.

For	Against	Abstain
17 ^{iv}	4	3

For
Responsibility to protect self and the whole society through vaccinating.
If you choose not to follow the rules for an organized program it is reasonable to be excluded from that program.
Against
It is not fair to exclude children from these activities.
Should only be excluded from these activities in the case of an outbreak.
With the education act everyone has a right to go to school in Canada.
Abstain
Children's right to an education and talents are not realized.

4. Exemptions from childhood vaccination are granted for medical reasons.

For	Against	Abstain
25	0	0

^{iv} The original vote was 24-0-1 but the group's position changed significantly after the policy panel discussion on the final day.

5. Acceptable ground for exemptions from childhood vaccination include conscience or personal beliefs.

For	Against	Abstain
5	16	4

“One thing that impresses me about Canada is the diversity and inclusion in Canada. There is so many diverse people in Canada and including everybody, and that’s a big thing for me. Now, with vaccinations I believe that I have a responsibility to the larger community, but I also have a responsibility to include those people that choose not to be vaccinated. And I think the moment that we start to exclude people, because of their choices, is the time that Canada loses its identity I think.” (Participant)

6. Conscience and personal beliefs are NOT grounds for exemptions from childhood vaccination^v.

For	Against	Abstain
16	5	4

For
Only medicine and science should be guidelines for exemptions.
Trust doctor’s expertise.
Abstain
Very complex issues, so what is a conscience or personal belief?
A grey area – what types of conscience and personal beliefs have been accepted?

^v Recommendation 6 is the negative form of recommendation 5. It was explicitly voted on to ensure that the framing of the statement (positive or negative) did not influence participants position.

7. Exemptions from childhood vaccination are granted on religious grounds.

For	Against	Abstain
6	11	8

For
Religions with issues with vaccination should be respected.
Canada is a diverse, tolerant country and can accommodate vaccine exemptions on religious grounds.
Against
No place for science and religion to mix.
Personal religious beliefs have no role in societal decisions.
We don't grant exemptions for texting and driving or drunk driving on religious grounds.
Abstain
Doesn't know enough about the different religious reasons.
Doesn't like the word "are" in the statement because we are making recommendations.
Religious grounds and personal beliefs are similar; when you start telling people what to do you run into trouble.

8. Parents or legal guardians should not be subject to incarceration if they chose not to vaccinate their children.

For	Against	Abstain
21	4	0

For
There are better incentive-based repercussions that could be used.
It would hurt the family; there have to be other ways.

ONTARIO VACCINE DELIBERATION REPORT

Avoid the cost to society of having to pay for the police, court system and childcare.
Consequences should fit the act; not vaccinating has nothing to do with jail.
There should be graduated consequences before this happens.
Against
If vaccination is made mandatory it is up to the courts to decide the consequences.
Jail is the punishment for non-compliance the law and it would be a valid application.
Jail could be one of many possible consequences.
Abstain
Should not jump straight to jail, there should be many steps before that.

9. Parents who do not have their children vaccinated, nor receive an exemption, shall face graduated consequences (e.g., warnings, mandatory education, and fines).

For	Against	Abstain
18	6	1

For
If you choose not to follow the law there should be consequences.
There should be consequences but the group is only making recommendations based on opinions and someone else needs to choose which to implement.
If you are affecting other people there should be a consequence.
Against
If we do a good job of persuading then consequences shouldn't be necessary.
When you start with warnings, there will just be more warnings.
Exclusion from schools and activities isn't sufficient and the cost of graduated consequences would be huge.
Consequence of exclusion from school is enough because homeschooling is hard.

Abstain
The language of warnings is too strong and education would be better.
Recommendations should encourage uptake and not focus on consequences.
Warnings is too mild and the language should be stronger so there is a hard line.

Communication about vaccines and vaccination

10. Ontario should provide a method of communicating publicly available information about childhood vaccination through multiple channels.

For	Against	Abstain
25	0	0

For
Attractive, non-coercive pamphlets sent with health card renewal notification.
Information should be presented clearly and simply to reach multiple education levels.

11. Information about childhood vaccination should be provided to parents during pregnancy and after the birth of their child.

For	Against	Abstain
25	0	0

For
More attention in giving information before the birth of the child.

12. Information about vaccination should be included throughout the school curriculum.

For	Against	Abstain
25	0	0

For
For both the parents and children; children let their parents know what happens in school and therefore both are getting education.

13. Information provided should be scientific and unbiased, addressing the risks, benefits, and concerns of childhood vaccination.

“Who would you trust? That’s a big part of it. I’m not trying to be a cynic about it, but who would I trust? The person who’s trying to sell me this [vaccines] or the person who’s trying to tell me, ‘look there are dangers involves and this is what they are?’ ... People said me, “wouldn’t you feel awful if your child got something or whatever [due to being unvaccinated]” and I said “yeah I would for sure, but I’d also feel really bad if I went against what I felt was the right thing for him right now and he got really sick” (Participant)

For	Against	Abstain
24	0	1

Abstain
Should include data analysis.

14. Information about vaccine safety and effectiveness that comes from multiple peer-reviewed scientific studies is better than information from other sources.

For	Against	Abstain
23	1	1

Against
There can be other information that is just as valuable (e.g., personal information).
Abstain
Sometimes personal experience, tradition, and religious beliefs are more powerful.

15. Public Health needs to think outside the box in communicating pro-vaccination messages and focus on social media, multi-media, advertising in public spaces, advertising in health professional offices, and other relevant educational outlets.

For	Against	Abstain
24	0	1

AEFI Compensation and Reporting

16. Serious *life-altering* adverse events from vaccination leading to diminished capacity should be compensated.

For	Against	Abstain
23	1	1

For
(Serious life-altering is) hard to define, but the recommendation is short with enough information.
Against
“Serious” covered everything in terms of adverse events.

17. A fund should be established with contributions from both the pharmaceutical industry and the government to compensate individuals who experience an adverse event following immunization (AEFI).

For	Against	Abstain
25	0	0

18. All AEFIs must be reported to the Public Health Unit by the medical professional to whom the incident was reported.

For	Against	Abstain
24	1	0

Against
Parents should also be able to report.

19. There must be follow-up by a health professional with a copy of the report sent to the parent following the report of an AEFI.

For	Against	Abstain
17	5	3

For
Follow-up could be something as simple as an email – we received the message, it is being processed.
The system is dealing with hesitancy and a lack of trust, by providing follow-up, it would work against these concerns in the greater public.
The reasoning was “what about the parents”, when the form gets sent in, the parents don’t get any information. By having follow-up, the parents know that the information was received.
Against
Following back up with the parent may be a lot of work; if the parent has more issues they can come back to the doctor.

If a parent reports it and it is nothing serious, it wouldn't need to go back to the doctor.
Seeing that AEFIs are generally serious, the reporting would be there.
Adds strain to the system.
Abstain
All AEFIs should not have follow-up, but the ones that are reported or diagnosed by a physician should be.
Follow-up is an ambiguous term - what is the deliverable?

20. There should be a national strategy for reporting and data collection relating to vaccination uptake, exemptions, and AEFIs. The provinces and territories should be incentivized to share all relevant data.

For	Against	Abstain
24 ^{vi}	0	0

^{vi} The total number of respondents for this vote was 24 rather than 25 because one participant left early.

Conclusions

Much public discourse on childhood vaccination is adversarial: pro-vaccine advocates lament the ignorance of “anti-vaxxers” and individuals with concerns about vaccines accuse pharmaceutical companies of putting profits before people and misleading public health advocates and members of the public. This environment makes it difficult for Canadian parents to make informed decisions about vaccination with confidence that they are acting in the best interest of their children. An adversarial environment also makes it difficult for public health officials and policy makers to engage meaningfully and sincerely with the broader public about concerns relating to childhood vaccination.

The Ontario Vaccine Deliberation is distinctive in that it constitutes a forum for members of the public to become informed about the issues, engage with each other and share diverse perspectives, and work toward collective conclusions. It is the only deliberative public engagement conducted on the topic of childhood vaccination to date in Canada. Although the Ontario Vaccine Deliberation does not have a formal mandate to influence policy, the recommendations it produced have strong democratic legitimacy as they represent the considered and informed reflections of a diverse group of Ontarians on issues relating to childhood vaccination.

In interpreting the outcomes of the Ontario Vaccine Deliberation, it is important to take into account several considerations. First, the recommendations of the forum are the outcome of several days of in-depth deliberation. These recommendations therefore represent the considered reflections of a diverse subset of the Ontario public; they are not a snap shot of the opinions of the general public on vaccination. Second, although forum participants were briefed about the current policies relating to childhood vaccination in Ontario (see information booklet), they were asked to deliberate about the issues from first principles, irrespective of the current policy context in Ontario. Third, although each deliberation question was approached with the goal of reaching consensus on a particular recommendation or position of the forum, a clear articulation of disagreement was also recognized as an important outcome. In particular, when disagreement on an issue persisted after sharing perspectives and considering issues from multiple points of view, this was seen to be valuable information that pointed to deeply held value differences in the broader Ontario public. Finally, vote counts need to be interpreted with care. The purpose of the voting was primarily as a tool for the facilitator to accurately gauge agreement and disagreement with collective propositions. After calling for a vote, the facilitator was able to identify individuals who disagreed or abstained and invite them to explain their position. This often led to refinement and reformulation of recommendations, and at other times helped articulate points of persistent disagreement. In some cases, abstentions and votes against a recommendation were based on modest differences (e.g., wording), with these participants still being in overall agreement with the direction of the recommendation.

The deliberative forum unanimously supported making childhood vaccination mandatory. This conclusion is particularly important in light of the fact that participants were chosen to reflect a diversity of opinions on vaccines, and participants explicitly considered promotional materials against childhood vaccination. Deliberants who had doubts about vaccines became convinced over the course of the deliberation of the soundness of public health advice for vaccination, as reflected most notably in the votes for Recommendation 2. However, there was persistent disagreement on the issue of what kinds of exemptions should be permitted. In particular, deliberants were divided on the issue of whether personal beliefs or religious convictions should be considered valid grounds for granting exemptions from vaccination. Most deliberants concluded that religious beliefs or personal beliefs should not be accepted as grounds for exemptions. However, a small number of deliberants who themselves would not make use of such exemptions felt strongly that such allowances should be made in Canadian society. We believe that this is an indicator of the success of the deliberation in that participants argued for positions that transcended their direct personal interests on the matter. We also feel that this is an important aspect of the conclusions of this public forum that should continue to be acknowledged in vaccination policy in Ontario: in spite of unanimous recognition of the health benefits of childhood vaccination, and in spite of recognition of the importance of high vaccination rates, a significant proportion of the forum maintained the position that individuals must have the right to exemptions based on religious and/or personal beliefs.

Deliberants recognized the challenges associated with the term “mandatory” in the context of requiring parents to show proof of immunization for their children. In general, it was assumed that vaccination status would need to be ascertained in connection with a child’s entry into the school system. Beyond that, deliberants recognized the difficulties associated with enforcing adherence to mandatory vaccination requirements. There was long discussion about what precisely was meant by mandatory. In particular, there was much discussion about what the consequences should be for children who are not vaccinated without valid exemptions and for their parents. A majority of deliberants concluded that children who are not vaccinated and do not have valid exemptions should be excluded from school and organized activities. There was persistent disagreement on this point, however, as several deliberants expressed that this violated children’s rights to education and exclusion should only be considered in cases of an outbreak. With regard to parents who do not have their children vaccinated nor have a valid exemption, a majority of deliberants concluded that they should face a series of graduated consequences, such as warnings, mandatory education, and fines. Although a minority of participants considered the option of incarceration of parents refusing to vaccinate their children for certain diseases, a strong majority rejected incarceration as a penalty based on reasoning that this would lead to greater harms for the child.

On the topic of communication about vaccination, deliberants advocated for broad educational programs and comprehensive communication strategies. Key points of deliberants’ recommendations included:

- Communicating about vaccination through multiple channels, including the possibility of including information at events such as health card renewal notifications.
- Providing information about childhood vaccination to parents and prospective parents specifically during pregnancy and after birth.
- Providing education about vaccination through the school curriculum.
- Information provided about vaccination should be scientific and unbiased, addressing the risks, benefits, and concerns of childhood vaccination.
- Alternative communication mechanisms, such as social media, should be considered.

In discussing the kind of information that should be communicated about vaccination, deliberants overwhelmingly emphasized reliance on peer-reviewed sources, preferably based on multiple studies. An important minority position in this context pertained to the role of personal experience. Over the course of the deliberation, some participants related experiences involving health care providers brushing off concerns about adverse effects from vaccination. This was of particular concern when an individual had experienced severe symptoms following a vaccination (irrespective of whether the vaccine had indeed caused the symptoms).

It should be noted here that Public Health does currently provide scientifically credible information via official websites. Although, as noted above, this provision of information has not contributed significantly to reducing vaccine hesitancy or refusal, the provision of impartial scientific information about vaccines to the general public is part of an important knowledge foundation for many Canadians.

Finally, deliberants considered the provision of no-fault compensation schemes for adverse events following immunization. There was strong agreement that there should be a compensation scheme either at the provincial or national level. There was unanimous agreement that such a compensation scheme should be funded through a combination of public and private funds (from pharmaceutical companies deriving profits from vaccines).

The forum recognized the importance of tracking AEFIs for purposes of ensuring vaccine safety. Accordingly, there was strong agreement on the need for reporting of AEFIs to public health units for the purpose of tracking adverse events. Only one deliberant disagreed with the recommendation that “All AEFIs must be reported to the Public Health Unit by the medical professional to whom the incident was reported” based on the recognition that some health professionals may not report or even recognize particular AEFIs. This deliberant emphasized that parents should also be able to report AEFIs directly.

On the whole, the conclusions of participants in the Ontario Vaccine Deliberation reflect a position that strongly supports childhood vaccination. This position relied on trust of the scientific practices underlying the technology and the public health institutions responsible for vaccination programs. This outcome should please public health professionals working in the field of childhood vaccination as it can be understood as a democratic endorsement of strong

vaccination programs and measures to ensure high uptake. However, some caution is advised in acting on this advice. In line with principles of deliberation, participants changed their views over the course of the deliberation. This was not a consequence of attempts to guide participants in any particular direction; rather, it was a consequence of the internal dynamics of the deliberative forum and deliberants working toward achieving common ground on the issues. This means that members of the broader public, who have not participated in such a process, will not automatically share the conclusions reached by this forum. In particular, individuals who do not accept prevalent scientific findings relating to the relative safety and efficacy of vaccines will likely not endorse or accept the conclusions reached by this public forum.

We believe that the relatively high degree of trust in scientific and public health institutions in Ontario that is implicit in the conclusions of the forum is in part due to the deliberative process itself. Participants came to understand the rationale of vaccination and the efforts and mechanisms in place to ensure the safety of vaccines much more deeply than they would have if they had just been exposed to the information in a passive way. Media discourse and scientific studies¹¹ suggest that some segments of the population have very little trust in communication about vaccines from official sources. The outcomes of the Ontario Vaccine Deliberation suggest that there is a high degree of latent trust in scientific and health institutions in Ontario. However, top-down, one-way communication from experts to the broader public about vaccines may appear paternalistic to some and thus risk eroding this trust. Instead, trust could be fostered by public health officials engaging with publics in dialogue more meaningfully, recognizing the importance of dialogue in making good individual and collective decisions. We believe that this was achieved on a small scale in this deliberative public engagement. Participants had a chance on the first day of the event not only to hear from experts on a range of issues relating to vaccination, but to ask questions and engage in conversation both collectively and individually during lunch and coffee breaks. Beyond that, participants were empowered to bring a range of perspectives to the discussion and in developing recommendations about vaccine policy in Ontario. Although it is not feasible for all Ontarians to engage in this kind of process, we believe that the outcomes of the Ontario Vaccine Deliberation demonstrate the principles of respectful and informed dialogue that can be used to de-escalate the polarized and adversarial positions currently characterizing discussions about childhood vaccination.

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Appendix A: Event Schedule

Ontario Vaccine Deliberation Agenda

October 14 & 15, and October 28 & 29

DAY ONE: October 14th

8:00 – 9:00 AM	Breakfast and check-in
9:00 – 9:15 AM	Welcome address
9:15 – 10:00 AM	Participant and research team introductions
10:00 – 10:20 AM	Overview of the event and ground rules
10:20 – 10:50 AM	Break
10:50 – 11:10 AM	Speaker 1: Natasha Crowcroft – <i>Public Health Perspectives on Childhood Vaccination</i>
11:10 – 11:30 AM	Speaker 2: Michelle Driedger – <i>Parental Concerns about Childhood Vaccines</i>
11:30 – 11:50 AM	Speaker 3: Rick Olazabal – <i>Advocating for Patients' Rights in the Age of Information and Confusion: The Other Side of the Coin</i>
11:50 – 12:10 PM	Speaker 4: Mina Tadrous – <i>Pharmacovigilance and Vaccine Safety</i>
12:10 – 12:30 PM	Speaker 5: Jim Brown – <i>The Eradication of Smallpox</i>
12:30 – 1:30 PM	Lunch
1:30 – 2:30 PM	Speaker panel discussion
2:30 – 2:40 PM	Introduction to Hopes and Concerns task and break-down of small groups
2:40 – 3:00 PM	Break (and reconvene in small groups)
3:00 – 4:00 PM	Small group discussions: Hopes and Concerns
4:00 – 4:45 PM	Large group discussion: Hopes and Concerns
4:45 – 5:00 PM	Overview of tasks and goals for Day 2

ONTARIO VACCINE DELIBERATION REPORT

DAY TWO: October 15th

8:00 – 9:00 AM	Breakfast and check-in
9:00 – 9:15 AM	Overview of tasks and goals for the day and introduction of deliberation question #1
9:15 – 10:15 AM	Small groups: Deliberation question #1
10:15 – 10:45 AM	Break
10:45 – 11:55 AM	Large group: Deliberation question #1
11:55 – 12:00 PM	Introduction of deliberation question #2
12:00 – 1:00 PM	Lunch
1:00 – 2:00 PM	Small groups: Deliberation question #2
2:00 – 2:30 PM	Break
2:30 – 3:45 PM	Large group: Deliberation question #2
3:45 – 4:00 PM	Are there questions we need to add to our agenda for Weekend 2?
4:00 – 4:30 PM	Overview of tasks and goals for weekend 2, brief survey, and check-out

DAY THREE: October 28th

8:00 – 9:00 AM	Breakfast and check-in
9:00 – 9:15 AM	Welcome back and overview of weekend
9:15 – 10:00 AM	Report back on questions from last weekend
10:00 – 10:20 AM	Break
10:20 – 11:20 AM	Small groups: Deliberation question #3
11:20 – 12:30 PM	Large group: Deliberation question #3
12:30 – 12:35 PM	Introduction of Deliberation question #4
12:35 – 1:30 PM	Lunch
1:30 – 2:30 PM	Small groups: Deliberation question #4
2:30 – 2:50 PM	Break

2:50 – 4:00 PM Large group: Deliberation question #4

4:00 – 4:30 PM Large group: Finalize questions for last deliberation session

4:30 – 5:00 PM Overview of tasks for Day 4

DAY FOUR: October 29th

8:00 – 9:00 AM Breakfast and check-in

9:00 – 9:15 AM Welcome back and overview of day

9:15 – 10:15 AM Small group: Deliberation question #5

10:15 – 10:45 AM Break

10:45 – 12:00 PM Large group: Deliberation question #5

12:00 – 1:00 PM Lunch

1:00 – 2:00 PM Large group: Review and revise recommendations for all deliberation questions

2:00 – 3:20 PM Expert and policy panel discussion

- Panelist 1: Michelle Driedger, PhD, Professor, University of Manitoba
- Panelist 2: Maya Goldenberg, PhD, Associate Professor, University of Guelph
- Panelist 3: Jennifer Potter, MD, family physician
- Panelist 4: Jacob Shelley, SJD, Assistant Professor, Western University
- Panelist 5: Alison Thompson, PhD, Associate Professor, University of Toronto
- Panelist 6: Frank Welsh, PhD, Director of Policy, Canadian Public Health Association

3:20 – 3:50 PM Break

3:50 – 4:30 PM Large group: Considerations arising from panel discussion and issues that need to be considered

4:30 – 4:45 PM Wrap up, brief survey, check-out and thank you!

Appendix B: Deliberation Questions

1. **How should vaccine policy respect parents' responsibilities to their children while reducing risk to other people?**

Many people see a tension between individual choice and societal obligation. In the context of vaccines, these may manifest in different ways. Please consider the following questions:

- A. In the context of vaccines, do parents have responsibility solely toward their own children, or do they also have responsibility toward the larger community?
- B. In the context of vaccines, if there is a trade-off between different responsibilities (e.g., toward own children and toward community), which one should take precedence?
- C. In the context of vaccines, who should have ultimate responsibility in deciding what is best for a child?

2. **Should certain childhood vaccinations be required in Ontario?**

Different states and provinces have different policies and laws with regard to vaccination. In Ontario, the law requires that children and adolescents attending primary or secondary school be appropriately immunized against designated diseases, unless they have a valid exemption. There are different ways in which governments can encourage citizens to engage in particular behaviours, such as passing laws, creating incentives, or “nudging” citizens to behave a certain way. Please consider the following questions:

- A. Should certain childhood vaccinations be required in Ontario? Or merely encouraged?
- B. What are acceptable grounds for seeking exemptions from vaccinations?

3. **How should information about vaccination and vaccination policy be communicated?**

For many parents the decision to vaccinate their children is straight-forward. For others, the decision is difficult. Difficulties may have to do with conflicting advice from different trusted sources, mistrust in information about vaccines, or other factors. Given this, please consider the following questions:

- A. What advice about vaccines should be provided to new parents?
- B. How should this information be provided?
- C. How can certain information sources be made more trustworthy?

4. What are appropriate responses when an adverse event related to a vaccination is reported?

Some parents are concerned about vaccinations causing harm. Although many alleged harms have not been found to be a result of vaccination, some harms of vaccines have been documented in the past (e.g., Cutter incident). Currently, adverse events are documented and reported in Ontario and these include both minor expected side-effects (some redness, swelling) and very rare unexpected serious complications. Given this, please consider the following question:

A. How should we address possible adverse events following immunization?

5A. What exactly do we mean when we say vaccination should be mandatory?

5B. What restrictions on unvaccinated children are justified?

5C. How should we provide parents with all of the relevant vaccine information?

Appendix C: Expert Presentations

Speaker 1: Natasha Crowcroft, MD/PhD (Public Health Perspectives on Childhood Vaccination). Available at: <https://osf.io/rg2mw/> (Part 1) and <https://osf.io/uewmy/> (Part 2)

Speaker 2: Michelle Dreidger, PhD (Parental Concerns about Childhood Vaccines). Available at: <https://osf.io/9fsr4/>

Speaker 3: Rick Olazabal, ND (Advocating for Patient's Rights in the Age of Information and Confusion: The Other Side of the Coin). Available at: <https://osf.io/4yzup/>

Speaker 4: Mina Tadrous, PharmD/PhD (Pharmacovigilance and Vaccine Safety). Available at: <https://osf.io/va2j5/>

Speaker 5: Jim Brown, PhD (The Eradication of Smallpox). Available at: <https://osf.io/5xr97/>