

# SUMMARY REPORT 2019



## Research Data Use in a Digital Society: A Deliberative Public Engagement



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## Executive Summary

New sources of public and private data and new ways to link them are constantly emerging. This offers new opportunities for research, new possibilities for using the results of that research, and new reasons for data-holding organizations to form partnerships. While research using these data can be beneficial, there is also a potential for negative consequences for some individuals or groups, a potential for consequences that are unintended and unanticipated by researchers and those collecting/collating the data, and a potential for misuse of by third parties. It is therefore important to consult the public on how we might achieve both opportunities to link different types of data for research purposes, and protections against the misuse of data and the possibility of negative consequences.

Combining data sources for research was the topic of a four-day meeting, *Research Data Use in a Digital Society: A Deliberative Public Event*, held in Vancouver, British Columbia (BC) on October 19-20 and November 2-3, 2019. This was a follow-up to a previous deliberation in April 2018 titled *Using Data About You for Research: Who, How, and Why*. The idea behind public deliberation events is that a diverse group of citizens comes together to give direct input, through carefully structured in-depth deliberations, to policy makers on issues that are controversial or a source of public concern. The goal is for participants, working together, to come to conclusions about the policy topic that accommodate their varied perspectives and reflect an informed public perspective. This process has democratic legitimacy and the ideas adopted, and programs and policies developed, are considered to be publicly informed.

Over the four days of meetings, 29 residents of BC discussed potential uses of publicly and privately collected data, partnerships for data-based research and what regulations are necessary to ensure that data are used in a trustworthy manner. Participants discussed issues including whether data from electronic medical records should be used for research purposes, whether it is acceptable to combine data from public and private sources, who should authorize its use in research, and how a public advisory group on data use might be structured. Deliberative conclusions from this public deliberation will help inform policy-makers as they begin to draft policies and amend legislation regarding the use and linkage of public and private data.



## Deliberative conclusions

Participants developed 17 deliberative conclusions that can be grouped into four broad topic areas:

### Balancing risk and benefit when linking data

- It is important that protections do not unduly restrict research using data.
- Combining public and private data is acceptable if due consideration is given to the mitigation of discrimination.
- It is acceptable to combine public and private data when the research has more potential for public benefit than risk.

### Expected protections

- The use of data must be peer reviewed and appropriate for the proposed research taking into consideration privacy issues.
- The research proposal involving the use of data must be peer reviewed.
- It is acceptable to combine public and private data when the data linkage is done by a trusted third party.
- The independent oversight review committees should have authority to hold researchers accountable for the appropriate use of data and impose consequences for non-compliance.
- The independent review committees being under government oversight (some supported and some objected).

### Authorization

- Informed consent should be considered when using genetic data.
- It is acceptable to use all medical data (including EMR) without consent, provided there is an option to opt out.
- Research that combines public and private data should be authorized by independent multidisciplinary committee(s) that include but are not limited to expertise in: ethics, law, commerce, science, and data management.
- Data from small communities should be considered for informed consent due to higher risk of re-identification.

### Ongoing public involvement

- An ongoing citizen advisory should be comprised of a diverse group of British Columbians, by diverse we mean in terms of: ethnicity, socioeconomic status, age, gender, education, geographic location, language, disability.
- Recruitment for an ongoing advisory should seek to create a public advisory as described above.
- It is important that an ongoing public advisory meet face to face; however, there should be an option to meet through other communication technologies as available.
- An ongoing public advisory should meet a minimum of twice a year and as needed.
- An ongoing public advisory should have membership terms of 2 years with 50% turnover annually.

## Introduction

### Why deliberate on new types of data and their future uses for research?

Living in a digital society means the use of computers and other information technology keeps increasing the amount of data collected about us. Everything from the time we wake up, to how we take our coffee, to how we commute can be collected by or through various public and private entities (i.e. data collectors), such as researchers, governmental agencies, doctors' practices, phone apps and devices from your Fitbit to your car.

Digital data are readily accessible and can easily be moved, shared and used. New sources of data and links across data sources and types offer new opportunities for research, new motivations to create partnerships across data-holding organizations and new possibilities for using the results of data analyses. These results could benefit society and the pace at which they can be applied may mean benefits accrue faster than they previously used to. However, combining public and private data for research, intended for the public good, could be used in ways that would negatively affect some individuals. Unintended consequences could lead to stigmatization of people or (for example) losing insurance coverage because of their health status. Moreover, because new analytical techniques and digital innovations are always being developed, future uses of data are unknown and hard to predict. The potential risk for misuse of data and the possibility of revealing private information, must be mitigated as part of establishing data linkage practices.

Combining data sources for research was the topic of a public deliberation event, *Research Data Use in a Digital Society: A Deliberative Public Event* held in Vancouver, British Columbia (BC) on October 19-20 and November 2-3, 2019. It was a follow-up to a previous deliberation in April 2018 titled *Using Data About You for Research: Who, How, and Why*. The results of the 2018 deliberation are published elsewhere<sup>1,2</sup>. Different participants were recruited for each deliberative event. One driving factor for organizing the deliberations was that BC has no provisions for how public sector and private sector data can be used together in either the *Freedom of Information and Protection of Privacy Act* (FIPPA, the legislation on use of public-sector data) or the *Personal Information Protection Act* (PIPA, the legislation for private-sector data).

The 2018 meetings developed conclusions on the rules and regulations for current use of linked data, while participants in the 2019 event considered rules and regulations that might ensure trustworthy governance of how new sources and types of linked data are used in the future. Because new uses for data are likely to emerge more rapidly than researchers, policy-makers, and the public can come together to discuss them, it might be wise to create a standing public advisory group that would be available to discuss data use and other pressing data-related issues.<sup>3</sup> We asked participants in the deliberation to discuss what a public advisory group to address emerging data issues should look like.

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#### What does it mean to link data?

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Linked data are collections of data that combine two or more data sets. In BC, for instance, a linked data set could be constructed by combining data sets from the Insurance Corporation of BC and BC Vital Statistics. Although it is currently not readily permitted, researchers are also interested in combining public data sets, such as Medical Services Plan data with those of private enterprises.

The project was organized by Population Data BC (a data holding and data linkage entity) and a research team from the University of British Columbia and the University of Guelph. A grant from the Canadian Institutes of Health Research supported the project.

## Principles of public deliberation

Public deliberation events are informed by political theory on deliberative democracy. The idea is that a diverse group of citizens comes together to give informed input, through carefully structured in-depth deliberations, on issues that are controversial or a source of public concern.<sup>4</sup> The goal is for participants, working together, to come to conclusions about policy that accommodate their varied perspectives. The process of public deliberations has democratic legitimacy and if deliberative conclusions are followed, they can help ensure programs, actions, and decisions will be accepted.<sup>5</sup>

The approach used for this public deliberation differs from other public consultations in many ways. Public consultations collect peoples' individual views, while deliberations create collective conclusions that reflect how participants think all their diverse interests are best accommodated.<sup>6</sup> Participants in deliberation events are given more background information, ahead of time and during the event, including expert speakers who give varying viewpoints on the subject matter. Discussions and the way participants create their deliberative conclusions are more in depth, with the whole process lasting several days.<sup>7</sup> The purpose of public deliberations is not to convince participants of any given position or bring them to consensus on the issues being discussed, but for participants to deliberate among themselves and reach either collective statements or deliberative conclusions that are acceptable to them as a group.

## Methods

### Recruiting participants

In order to capture a broad range of life experience and perspectives, participants were selected to reflect the diversity of age, sex, income, self-identified ethnicity, and geographic region of BC residents. The only group explicitly excluded were people who work as privacy professionals; in public deliberation, it is best to avoid including "experts," (with respect to the topic at hand) because participants tend to defer to them, which undermines the deliberation process.<sup>8</sup>

Participants were recruited from all age groups and special effort was made to recruit hard to reach groups, such as 18-24 year-olds, Indigenous persons, and those living in remote regions of BC, since these groups tend to be under-represented in public discourse and their perspectives are important to informing the overall deliberations.<sup>9</sup>

To recruit participants, a direct marketing company was engaged to mail letters of invitation to participate to 10,000 randomly selected households from all parts of BC (the research team did not select the households). Household addresses were provided to the marketing company by Canada Post. Interested residents were asked to complete an online questionnaire on their demographic information, availability to participate in the deliberation, and to confirm they were not privacy professionals. Nearly 300 BC residents responded and met the eligibility criteria. Potential participants were then selected randomly from the eligibility pool and stratified to BC census data,

with attention to including those from under-represented groups. Details of the demographic composition of the participants are in Appendix A.

Twenty-nine (29) members of the BC public participated in the deliberation on the first weekend, with 28 participating on the second weekend (one person left because of a family obligation). The cost of travel, meals and accommodation was covered by project funding. Each participant also received a \$125 honorarium per day of attendance.

## Informing participants

Participants were encouraged to bring their opinions, values, and ideas about the topic to the deliberation but were not required to have prior knowledge of the use of linked data for research. To support their discussions and ensure they all had the same basic knowledge, a plain language information booklet<sup>10</sup> was provided two to three weeks before the meeting, and expert speakers gave presentations on the first day. The goal was to provide a broad range of views on the issues central to the deliberation so participants could be well-informed when engaging with and responding to other participants.

The information booklet was developed using both expert knowledge and academic literature. It described what linked data are, how they are collected, what regulations are in place for sharing them, and issues and concerns surrounding their use. The intent was for the material to be presented at a grade 10 reading level. A glossary provided definitions of technical terms. The booklet was provided in both digital and physical formats.

The speakers at the event were Wendy Hurlburt, President and CEO of Life Sciences BC, Holly Longstaff, Director, Privacy and Access, Provincial Health Services Authority, Meghan McDermott, Staff Counsel, BC Civil Liberties Association, and Sabrina Wong, Professor, School of Nursing and Centre for Health Services and Policy Research. The speakers also took part in an informal panel and answered participant questions.

## Deliberative process

The event format followed deliberative public engagement methods developed by Burgess, O'Doherty et al.<sup>11</sup> which have been used in previous deliberation events.<sup>12-14</sup> The four-day event was run by facilitators trained specifically for this type of public deliberation and occurred on two non-consecutive weekends, with the break in between designed to give participants time to reflect on their discussions and discuss the topic with their families and friends.

During the event, participants met as a whole and also in four small groups of 6 to 8 participants that remained the same for both weekends. The small group deliberations are designed to encourage everyone to participate in generating a broad range of viewpoints on the topics being discussed. The large group deliberations brought the diverse views from the small groups to bear on the issues the group as a whole considered important. Participants then all worked together to craft deliberative conclusions on policy related to the use and sharing of linked data. Their arguments for and against the conclusions were also captured.

Participants were asked to develop recommendations for decision-makers developing policy on data-use issues. However, it was subsequently concluded the word “recommendation” was the wrong one to describe what the participants came up with. In some cases, the participants made



statements that reflected a point of view they all held and wished to communicate to the policy-makers. In others, where there was not agreement, the participants voted on differently worded versions of statements to test whether their ideas converged. For simplicity, we refer to all of these as “deliberative conclusions.” As the pie graphs beside each deliberative conclusion show, response to some statements was quite split, meaning many participants disagreed. It is important to highlight those disagreements for policy-makers, because they identify topics or activities that need to be approached with greater caution because there is greater uncertainty about the public’s views. Put another way, a group that managed to converge on common conclusions in some cases not finding convergence in other suggests there is a substantive controversy that is not resolved with good information or a focus on the common good.

The first day of the event focused on informing participants about using and sharing linked data for research and introducing them to the process of public deliberation. Expert speakers gave presentations and answered participants’ questions. Participants were told if they needed more information the research team would find it and present it to the group on subsequent days.

The second and third days were used to discuss the deliberation questions, with the participants discussing each question in their small groups, then returning to the large group to discuss the issues and perspectives raised in the small groups. The facilitator helped formulate the points raised into preliminary statements, which participants edited until they arrived at a collective statement that represented the conclusion of their deliberations. Participants then voted for or against the statement, or abstained, with each person explaining their reasons for taking their position.

On the fourth day the deliberative conclusions were summarized and reviewed, and participants had the chance to vote again if new information and perspectives had changed their minds. The meeting concluded with a panel of experts who are in positions to influence policy on sharing linked data for research. They were Hayden Lansdell, Assistant Deputy Minister of Digital Platforms and Data in the BC Ministry of Citizen Services, Kimberlyn McGrail, Scientific Director of Population Data BC, and Alison Pearce, Chief Privacy Officer for the BC Ministry of Health. The panel members listened to the deliberative conclusions and then discussed them with participants.

The proceedings were audio recorded and transcribed; detailed analysis of the transcriptions is underway. All procedures for this research project were reviewed and approved by the UBC Behavioural Research Ethics Board (Certificate # H19-01765). See Appendix B for the event’s schedule.



## Deliberation questions

Deliberative questions were developed by the research team, informed by consultations with data stewards and policy makers on current and relevant data-based issues, to ensure the deliberations focused on topics that can be actionable by policy-makers. Four questions were given to participants to discuss. Each included scenarios designed by the research team to encourage discussion.

Participants were asked to start by discussing the deliberative questions and scenarios and to gather feedback on them, identifying concerns and what they would recommend as a way to proceed. They were then encouraged to talk their way through to collective positions that took into consideration the different perspectives heard in the small group, in order to present them to the large group as deliberative conclusions.

See Appendix C for the complete list of deliberation questions and the scenarios used for each of the questions.

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### Deliberation questions

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1. Under what conditions is it acceptable to use data from electronic medical records for research?
2. Under what conditions is it acceptable to combine private sector and public sector data for research?
3. Who needs to authorize research that combines public and private data?
4. What are important features of an ongoing citizen advisory for decisions about data-based research in BC?

## The participants' deliberative conclusions

As participants considered the deliberation questions, they developed conclusions on a variety of topics that related to the questions. To facilitate interpretation and reporting, the deliberative conclusions the participants developed were grouped into four emergent categories rather than in the order they were developed during the event. We use these categories rather than the deliberation questions to organize reporting results, as the questions were meant to seed discussion not to direct or constrain it. The emergent categories are:

1. Balancing risk and benefit when linking data;
2. Expected protections;
3. Authorization;
4. Ongoing public involvement.

Although the participants voted on the deliberative conclusions, the total of those votes should not be over-interpreted. Voting was a tool the large-group facilitator used to assess convergence on a position and to identify the reasons in support of it. For example, while some participants who voted against a deliberative conclusion were truly opposed to it, others who voted against it may have had issues only with the conclusion's wording, sometimes because they wanted to take an even stronger position. After each vote, the facilitator identified individuals who disagreed or abstained and ask them to explain their positions. In cases where there were disagreements on the deliberative conclusions, clear articulation of the disagreement was recorded and the arguments on both sides

because disagreements and the reasons for them can clarify what trade-offs are acceptable to the public and can thus inform policy scope.

In addition, the voting tested the limits of participants' agreement on issues by reflecting how they responded to slightly different versions of a particular deliberative conclusion (e.g., by including different wording or adding or omitting a concept). The votes helped isolate and identify what aspects of the conclusion participants agreed or disagreed on. The examples where there were multiple versions of conclusions are indicated below, and whether that affected participants' convergence of opinions noted.

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### Vote results

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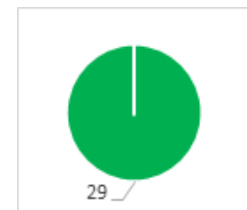
Each pie chart shows the vote on that deliberative conclusion. Green = votes for, orange = votes against and grey = abstentions. The number of votes for each category is shown on the pie chart.

## Balancing risk and benefit when linking data

Participants confirmed general support for linking and using data, with some important considerations that underlie many of the deliberative conclusions.

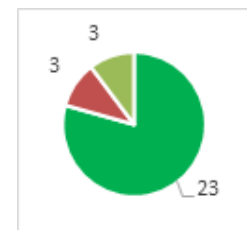
### *Combining public and private data is acceptable if due consideration is given to the mitigation of discrimination*

Participants discussed the possibility that research on shared data sets could lead to discrimination against certain segments of the population, such as different age groups applying for insurance or people with certain health conditions looking for job opportunities. Participants unanimously agreed combining public and private data should only be used for research if there is reasonable certainty that this would not result in stigma or discrimination.



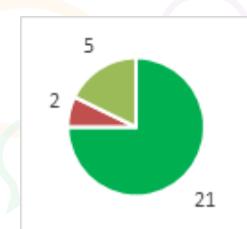
### *It is acceptable to combine public and private data when the research has more potential for public benefit than risk*

Participants recognized the potential benefits of research using combined public and private data, but worried about risks such as data breaches (while recognizing that risk cannot be fully eliminated). Those in favour found combining public and private data acceptable if it would bring more public benefit than harm. Those against thought a stipulation requiring more public benefit would deter private corporations from being involved in research, because it might reduce profits. Abstainers were concerned about using the word "potential" in the conclusion, which they felt left it too open to interpretation.



### *It's important that protections don't unduly restrict research using data*

This conclusion arose from participants' concern that excessive regulation could prevent research being done. Most participants thought it was important to maintain researchers' ability to pursue their interests (i.e. academic queries). Participants who were against the conclusion worried review processes might be unjustifiably rushed and protections would not be considered sufficiently. They also raised the question of how to balance the importance of research and privacy.



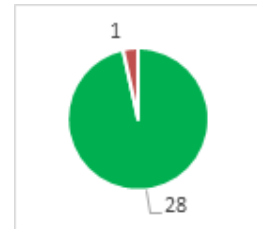
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## Expected protections

How to regulate, control and manage the sharing and use of linked data (i.e. data governance) were issues that arose continually throughout the two weekends. Generally, participants' conclusions called for secure and trustworthy processes to ensure potential abuses would be prevented, or caught and stopped.

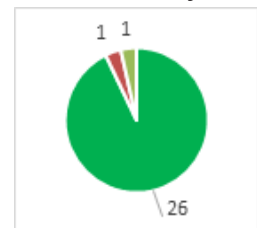
***It is acceptable to combine public and private data when the data linkage is done by a trusted third party***

Participants felt strongly that linking public and private data sets should be conducted by a trusted independent body. In addition, a strong majority wanted that body to be free from ties to government, because of underlying mistrust of government intentions and the risk that political interference will thwart research. The person who voted against the conclusion disagreed that government could not be trusted.



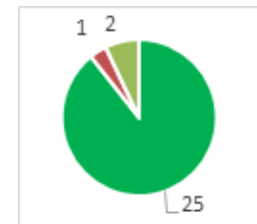
***The use of data must be peer reviewed and appropriate for the proposed research, taking into consideration privacy issues***

This conclusion resulted from concerns over the risk to privacy some research presents (for example, research on small communities or rare diseases, where it might be possible to identify the people involved). Participants felt strongly that research proposals must be reviewed to identify privacy risks, and suggested that assessment could be part of peer reviews. The participant who voted against the conclusion objected that peer reviewers, whose job is to evaluate scientific value, are not privacy experts. The participant who abstained said the conclusion was too limited because it only mentioned privacy while excluding considerations such as other ethical issues.



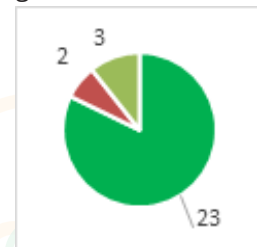
***Research proposals involving the use of data must be peer reviewed***

Participants were in favour of having research using linked data sets peer reviewed. The participant who opposed the conclusion said it was too limited because it did not address concerns such as privacy or citizens who might be affected by the research. The participants who abstained said the wording of the conclusion was too vague.



***The independent oversight review committees should have authority to hold researchers accountable for the appropriate use of data and impose consequences for non-compliance***

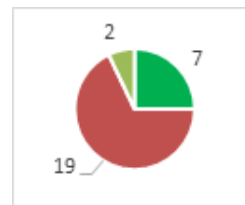
During their deliberations, participants agreed there should be meaningful consequences if a researcher (or anyone) misuses data, and were concerned current consequences are too slight to deter people who misuse data. Participants suggested an oversight committee could have power to punish non-compliant researchers, perhaps with fines or by revoking privileges to use data. The participants who disagreed were uncomfortable with a committee having authority to punish and wanted consequences to be more than just financial. The participants who abstained said this type of oversight and consequences would discourage researchers from doing their work.



***The independent review committees should be under government oversight***

Participants could not reach consensus on the nature of the review committees' independence.

Most participants disagreed with government oversight of linked data and the conclusion presented here was written and voted to capture the extent of division on the issue. The opposing majority felt the government could not be trusted to oversee data use and also wanted to separate the powers of the government and the oversight committee. Those who supported government oversight said the government had people's best interests in mind and are representative of the people who voted for them. They also said basic trust of the government is necessary because it would be up to government to intervene if the review committees disagree.

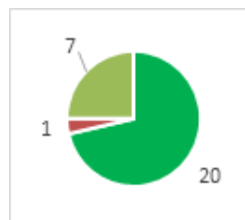


## Authorization

These deliberative conclusions reflect how participants' discussion shifted from the general concept of authorization to the more specific topic of consent, particularly informed consent. Participants were concerned about consent throughout the deliberation. Their concerns about informed consent were related to data ownership and people's power to retain control of their data. While not specifically raised in the booklet or by speakers, genetic data was also a key concern for participants who felt it was unique among forms of data.

### ***Informed consent should be considered when using genetic data due to higher risk of unjustified discrimination***

This deliberative conclusion included provisions regarding the main concerns of the participants: being discriminated against on the basis of their genetic data. The participant who voted against wanted a stronger verb than "should". The participants who abstained disliked the term "unjustified discrimination." They thought "discrimination" was a very powerful word, and although they understood that discrimination can sometimes be justified they were uncomfortable with the prefix "un". Others who abstained said genetic data is fundamentally different from other types of data and would always carry higher risk when used.



Two additional versions of this conclusion were developed to see whether participants would converge on a conclusion if certain elements were removed or modified; however, the proportion of support shifted only slightly with each version, although it was different participants who changed their votes, showing preferences for each version varied.

#### ***Second version:***

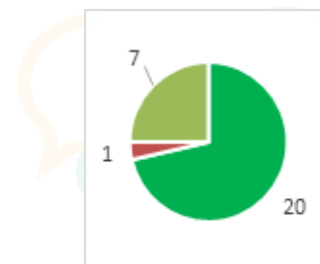
### ***Informed consent should be considered when using genetic data***

The second version was developed to test whether there would be any change in support if "unjustified discrimination" was removed. This more general conclusion garnered 20 votes in favour, for similar reasons as the original conclusion.

#### ***Third version:***

### ***Informed consent must be considered when using genetic data***

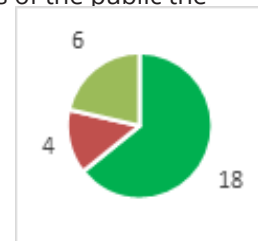
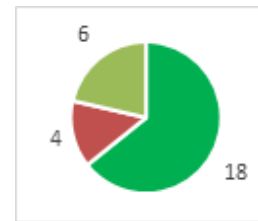
The third version of the conclusion was developed to test whether there



would be support if “should” were changed to “must;” instead, the level of support dropped slightly. Those who voted against or abstained said “must” was too absolute and might constrain research activities.

***It is acceptable to use all medical data (including EMR) without consent, provided there is an option to opt out***

This conclusion was developed when researchers asked the participants to consider consent for use of medical data, which participants had been discussing without converging on a specific statement. This conclusion was developed to enable beneficial research using EMRs, while giving members of the public the option not to be included in such studies. Those in favour thought the conclusion would enable important research while providing sufficient opt-out provisions, and thought medical data were different from genetic data. Those opposed to the conclusion were concerned that individuals might be identified. They also did not want their data to be used without knowing what for. Abstainers said they supported the conclusion in principle, but felt even the current data uses do not always adequately protect privacy.



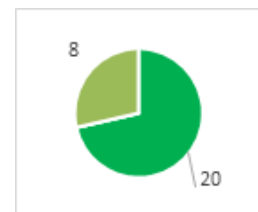
***Research that combines public and private data should be authorized by multidisciplinary committee(s) that address ethical, legal, commercial, content, and data management concerns***

Most participants wanted a multidisciplinary committee to have the power to approve research based on researchers’ ability to satisfy concerns on a range of issues. Participants who abstained thought the conclusion didn’t go far enough and was too vague; their concerns over its wording and the responsibilities of the committee led to a second version.

***Second version:***

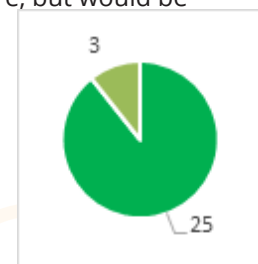
***Research that combines public and private data should be authorized by independent multidisciplinary committee(s) that include but are not limited to expertise in: ethics, law, commerce, science, and data management***

The second version, which received more support, specified that the committee must be independent and changed the wording about its scope to make it more inclusive. Those who abstained were concerned that the format of the committee was unknown and thought having a committee might make research less efficient. They also thought an independent committee would still require oversight, e.g. that policies might be set elsewhere, but would be implemented by this committee.

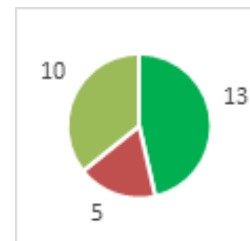


***Data from small communities should be considered for informed consent due to higher risk of re-identification***

Participants were divided over this conclusion, which was intended to increase protection for residents of small communities, who have a higher risk of being identified in research. Only a minority voted in favour, some of



whom felt informed consent should be requested whenever the sample size relative to the population size might result in re-identification. Those opposed said data should be treated equally regardless of community size and thought existing ethics rules were sufficient to protect the privacy of small communities. Those who abstained recognized individuals could potentially be identifiable in data from small communities.



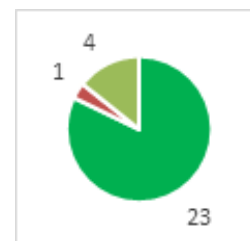
## Ongoing public involvement

New means of collecting and analysing data are being developed rapidly, making it impossible to anticipate what they might be and their impact on individuals and society. One mechanism to help address these issues may be to create a standing public advisory group to discuss new uses for data and other data-related issues.<sup>3</sup> Several different models of data advisory groups have been established elsewhere, including, the National Institute for Health and Care Excellence Citizens Council in the UK and the Health Forum at McMaster University in Hamilton, Ontario. On the final day of the deliberation, participants were asked what they considered important features of such an ongoing citizens advisory.

***An ongoing citizen advisory should be comprised of a diverse group of British Columbians; by diverse we mean diversity in terms of: ethnicity, socioeconomic status, age, gender, education, geographic location, language, disability***

Most participants supported this conclusion because they felt it important to include a diverse group of British Columbians. The participant who voted against it did not think “language” should be included. Those who abstained found the conclusion too vague and “politically correct”. They felt diversity was good in theory but too difficult to implement in practice.

Two versions of this deliberative conclusion were developed because participants wanted to see if removing “language” from the criteria for diversity would garner more support. To clarify the idea of diversity, researchers explained the differences among proportional, representative and normative diversity; 15 participants chose normative diversity, which actively seeks to include under-represented voices. However, participants ultimately disagreed on the specific criteria for diversity.



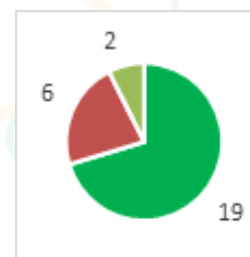
***Second version:***

***An ongoing citizen advisory should be comprised of a diverse group of British Columbians, by diverse we mean in terms of: ethnicity, socioeconomic status, age, gender, education, geographic location, disability***

The second version of the conclusion removed “language” as an indicator of diversity but received less support. Those in favour thought ethnicity was sufficient to ensure diversity. Participants also said since British Columbians must interact with the provincial government in English, they should be able to speak it. Those who opposed were concerned that removing “language” would be discriminatory and possibly exclude populations, such as those living in remote areas who do not speak English.

***Recruitment for an ongoing advisory should seek to create a public advisory as described in deliberative conclusion #12***

Participants wanted to ensure recruiting for the public advisory group would match the diversity they strongly supported in the deliberative conclusion

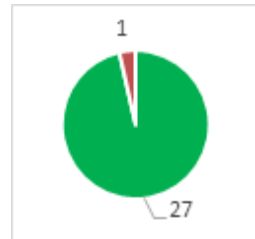
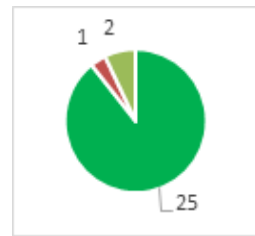




above. Those who voted against this conclusion did so because they had not supported aspects of the previous statement.

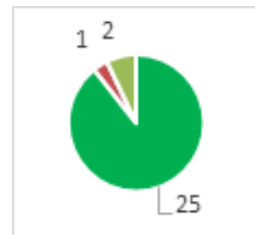
***It is important that an ongoing public advisory meet face to face; however, there should be an option to meet through other communication technologies as available***

When participants discussed the logistics and costs of running a standing advisory group on data use, they recognized it would be expensive to bring advisory members from across BC to meet face-to-face. However, they felt that meeting in person was important to develop rapport and a working relationship among members. The participants strongly supported the conclusion but added that using online meeting technology should be an option. The participant who voted against said face-to-face meetings were too costly and using technological means to gather opinions would be sufficient.



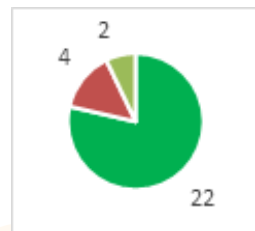
***An ongoing public advisory should meet a minimum of twice a year and as needed***

Participants strongly supported this deliberative conclusion. When participants talked about how often the public advisory group should meet, they discussed some of the inherent difficulties of recruiting and scheduling, for instance, that it can be difficult to recruit people with children in the summer and difficult to recruit people who live in remote areas during the winter. “As needed” was added to the conclusion after participants were told that if there is nothing to discuss at a scheduled meeting, participation can fall off. The participant who did not support the conclusion thought an advisory group was an inappropriate use of taxpayer money. One abstainer wanted the advisory group to meet quarterly, while the other wanted annual meetings. Both were concerned the term “as needed” did not specify who would determine when meetings were necessary.



***An ongoing public advisory should have membership terms of two years with 50% turnover annually***

Participants developed this deliberative conclusion in part because they learned that participants who serve on an advisory too long may become more knowledgeable and no longer truly reflect public opinion. Their suggested approach of two years per term and 50% turnover annually means that every year half of the advisory members complete their term, thus ensuring half the group remain and can share their knowledge with the new members. The participants supported structure, although there was still uncertainty about the frequency of meetings. Those opposed said the length of membership terms should depend on how often meeting are held and the topics discussed. Those who abstained from voting said they could not comment because the idea was too conceptual, without knowing meeting frequency or topics.



## Conclusions

The possibilities for research using linked data are evolving quickly. Such research creates



opportunities to produce knowledge that benefits the public, but it also creates risks, including the possibility of identification. These concerns need to be addressed by policy makers, while also considering the diversity in the perspectives and interests of the public, in order to develop policies, procedures, and guidelines that balance the benefits of the research with their risks.<sup>16</sup> Doing so will help in developing data sharing processes that are safe, trustworthy, and acceptable to the public.

The deliberative conclusions developed by the participants fall into four broad categories which are interdependent. There is broad and clear support for research using linked data, but always with specific context or expectations. In many cases, the participants indicated that their support for a given deliberative conclusion was dependent on a previous deliberative conclusion. For example, the acceptability of using medical and EMR data without consent was contingent on having an oversight committee that assessed the research for ethical, privacy, and security concerns.

Participants identified that obligations come with the use of sensitive linked data. In many cases, participants objected to certain proposed regulations was based on the concern that they would lead to unnecessary barriers to conducting promising research and thus deter the research from being conducted altogether. This was represented in discussions around conditions requiring informed consent, such as with research involving residents of small communities.

Participants especially recognized a need to protect individuals in vulnerable populations (e.g., Indigenous peoples and people with rare diseases) and in small communities, due in part to a heightened risk of being re-identified.

Overall, this public deliberation event produced 17 deliberative conclusions for consideration by policy-makers. This report provides a summary of those deliberative conclusions and the reasoning provided explicitly through facilitated discussion following voting. Further analysis is underway to provide greater insight on the process of the deliberations and the context around specific deliberative conclusions.



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## Appendix

### A. Participant demographic composition

We made a specific effort to recruit individuals who are younger (aged 18-24) as previous deliberations have found this group difficult both to recruit and retain. We also focused on recruiting people who identified as Indigenous, as there are distinct norms and practices around data and data sharing in Indigenous communities that were important to reflect in the deliberations. Finally, we made efforts to recruit people who live in remote regions of BC, selecting people based on their Metropolitan Influence Zone (MIZ), a measure that shows whether an area with a low population density is truly remote or located close to a metropolitan area

#### Gender:

Male: 15  
Female: 13  
Other: 1

#### Age:

18-24: 3  
25-34: 4  
35-49: 10  
50-64: 6  
65+: 6

#### Education:

University or above: 15  
Some university: 5  
High school: 3  
College or apprenticeship: 6

#### Ethnic identity:

African American: 2  
Caucasian: 16  
East Asian: 6  
First Nations: 2  
Metis: 1  
Mixed race: 1  
South East Asian: 3

#### Geographic location:

Vancouver Coastal: 8  
Fraser Valley: 7  
Vancouver Island: 4  
Northern BC: 6  
Interior BC: 4

#### Metropolitan Influence Zone:

1: 21  
2: 3  
3: 2  
5: 2  
6: 1  
7: 1



## B. Event Schedule

### DAY ONE: October 19th

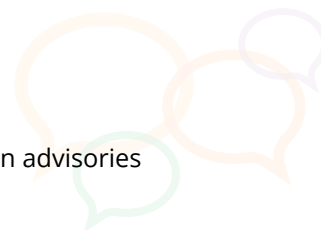
8:00-9:00 AM	Breakfast and check-in
9:00-9:15 AM	Welcome address
9:15-10:00 AM	Participant and research team introductions
10:00-10:20 AM	Overview of the event and ground rules
10:20-10:40 AM	Break
10:40-11:00 AM	Sabrina Wong, PhD, Professor, School of Population and Public Health, University of British Columbia
11:00-11:20 AM	Wendy Hurlburt, CEO of LifeSciences BC
11:20-11:40 AM	Meghan McDermott, Staff Counsel, BC Civil Liberties Association
11:40-12:00 PM	Holly Longstaff, Director Privacy and Access, Provincial Health Services Authority
12:00-1:00 PM	Lunch
1:00-2:00 PM	Speaker panel discussion
2:00-2:10 PM	Introduction to Hopes and Concerns task and break-down of small groups
2:10-2:30 PM	Break (and reconvene in small groups)
2:30-3:30 PM	Small group discussions: Hopes and Concerns
3:30-4:15 PM	Large group discussions: Hopes and Concerns
4:15-4:30 PM	Overview of tasks and goals for Day 2

### DAY TWO: October 20th

8:00-9:00 AM	Breakfast and check-in
9:00-9:30 AM	Overview of tasks and goals for the day, and introduction of deliberation question #1
9:30-10:30 AM	Small groups: Deliberation question #1
10:30-10:50 AM	Break
10:50-11:50 AM	Large group: Deliberation question #1
11:50-12:00 PM	Introduction to Deliberation question #2
12:00-1:00 PM	Lunch
1:00-2:00 PM	Small groups: Deliberation question #2
2:00-2:20 PM	Break
2:20-3:30 PM	Large group: Deliberation question #2
3:30-3:45 PM	Are there questions we need to add to our agenda for Weekend 2?
3:45-4:00 PM	Overview of tasks and goals for weekend 2, check out

### DAY THREE: November 2nd

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; introduction to deliberative question #3
10:10-11:10 AM	Small groups: Deliberation question #3
11:10-11:30 AM	Break
11:30-12:30 PM	Large group: Deliberation question #3
12:30-1:30 PM	Lunch
1:30-3:00 PM	Large group discussion
3:00-3:20 PM	Break
3:20-3:30 PM	Introduction to Q4 on citizen advisories
3:30-4:30 PM	Small group: Deliberation question #4 on citizen advisories
4:30-4:45 PM	Overview of tasks for Day 4



## DAY FOUR: November 3rd

8:00-9:00 AM	Breakfast and check-in
9:00-9:15 AM	Welcome back and overview of day
9:15-10:15AM	Large group: Deliberation question #5 on citizen advisories
10:15-10:35 AM	Break
10:35-11:35 AM	Large group: Review and revise recommendations
11:35-12:00 PM	Group photo!
12:00-1:00 PM	Lunch
1:00-1:30PM	Final questions: Is there anything we didn't get to?
1:30-2:30PM	Expert and policy panel discussion
2:30-2:50PM	Break
2:50-3:15 PM	Large group: Considerations from policy panel discussions
3:15-3:45 PM	Wrap up, check-out, and thank you!



## C. Scenarios to aid discussion for the deliberation questions

### **Deliberative question 1: Under what conditions is it acceptable to use data from electronic medical records for research?**

Scenario 1: A researcher is interested in investigating the potential link between medicine use to treat hypertension among older adults and later development of dementia. In order to do this research; she needs access to data for a large number of people. The data would include: age and sex; year of original diagnosis of hypertension, blood pressure readings over time; the names and doses of prescribed drugs; and signs, symptoms and/or measures of dementia. Some of these data could come from administrative data, but some (like blood pressure readings, measures of dementia) would only be available in electronic medical records.

Scenario 2: A researcher is interested in developing new genetic tests that could be used to identify whether people might have a bad reaction to a drug, or whether different choices in drugs might be more or less effective. This idea is a form of “precision medicine” but how well it might work is unknown; this is the reason for the research. This research needs as much detailed health history as possible, from electronic medical records and other sources, as well as a genetic profile that would be linked to those other data. If successful, the intent is to include genetic profiles in electronic medical records, and to commercialize the testing procedure.

### **Deliberative question 2: Under what conditions is it acceptable to combine private sector and public sector data for research?**

*Scenario 1:* Driver factors such as speeding, distraction, and impaired driving play a major role in most fatal and injury crashes. Many drivers use medications that may slow their reaction time, cloud judgment and impair the psychomotor skills required for safe driving. This potential threat to road safety may be increasing due to an aging population and increased use of psychotropic (or impairing) medications. Currently, despite international efforts, the risk to road safety associated with most medications is poorly understood. This knowledge gap hinders the development of effective policy, social marketing campaigns, and medication warning labels targeting people who drive while using impairing medications. Researchers hope to address this knowledge gap with research using data on health care and deaths linked with data from ICBC.

Scenario 2: The likelihood of being diagnosed with cancer increases with age, and it is known that both genetic and environmental factors influence the risk of cancer. Researchers are interested in getting a better understanding of this risk, and specifically the influence of diet. They are proposing a study that would link data on demographics, health care services use, education, and occupation information with data on grocery shopping drawn directly from large supermarket chains. The desire is for a very large research study, so there is no intent to have direct contact with anyone whose data are used in the study.

### **Deliberative question 3: Who needs to authorize research that combines public and private data?”**

Scenario 1: A group of family physicians is interested in replicating a study done in Spain that looks at differences in outcomes when people take hypertension medication at bedtime vs. in the morning. (The Spanish study, which was small, but suggested a 30% decrease in cardiovascular

events.) This research requires linkage of EMR data and administrative data and would benefit from linkage to home health monitoring data held by a private company.

Scenario 2: Researchers are interested in better measures of and predictions of frailty and think that combining a number of different data sets will give them better information to create a good predictive tool. They want to use EMR data including clinical notes, plus patient-reported information, information from apps on mobility and activity, public and private information on care aides, administrative records, and information on social supports like home care to do their research.

Scenario 3: Policy makers have increasing concerns about early childhood experiences and health and educational outcomes in later life. Researchers want to link early development data, health data, education data, app-based fitness data, and grocery shopping habits, and ideally income and occupational information to understand different pathways and identify important events or triggers that might lead to better or worse outcomes. This research intends to include as large a population as possible and does not need direct contact with participants.

#### **Deliberative question 4: What are important features of an ongoing citizen advisory for decisions about data-based research in BC?**

*Scenario:* Imagine that the BC Government has come to you for advice about how to obtain **ongoing public input** into decisions about data-based research in BC. The provincial government is looking for advice from members of the BC public on challenging issues similar to the ones we have discussed over the two weekends of this deliberation, namely, about the possible uses and applications of data-based research. They want to find out what's important to people about these issues, what their values are and how we can make decisions that are acceptable to the people of BC.

Considering what you have heard so far in this deliberation and your own opinions about how an advisory could work, what advice would you give to the government?

