

Appendix 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: Under what conditions is it acceptable to use data from electronic medical records for research?
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: Under what conditions is it acceptable to combine private sector and public sector data for research?
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: Who needs to authorize research that combines public and private data?
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 deliberative question #4: What are important features of an ongoing citizen advisory for decisions about data-based research in BC?
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
9:15-10:15 AM	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!

Appendix 2

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 commercialise 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 authorise 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?



Appendix 3

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
 White: 16
 East Asian: 6
 First Nations: 2
 Metis: 1
 Mixed race: 1
 South East Asian: 3

Geographic location based on the five geographic health authorities in British Columbia:

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

Metropolitan Influenced Zone: This is a categorisation of geography that is based on commuting patterns between smaller and larger population areas. It is intended to capture the degree of influence of a larger city (e.g. proximity) to cities or towns with smaller populations. This is graded from metropolitan areas (1) to rural / remote areas far from any metropolitan zone.

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

