## Appendix F: Peer review feedback

### F1 – Process for peer review

Before the report was finalized, it was sent to a group of peer reviewers for comment. The peer reviewers were experienced public and patient advisors who had applied to be participants, but had not been selected because there were other applicants whose involvement increased the diversity of the participant groups. Peer reviewers were provided a $25 Canadian honorarium.

There was no intent to modify the content or main findings of the report based on peer reviewer feedback, because peer reviewers worked on their own at one point in the process, in contrast with the participants who engaged in dialogue with each other over multiple weeks. However, we did want to know peer reviewers’ views to see if they had any major disagreements with the report content and to ensure that the document would be understandable for people who had not been part of the process.

Peer reviewers were asked three questions:

1. Do you disagree with any of the statements presented in the report?
2. Is there anything essential you believe to be missing from the report?
3. Do you have any other comments or feedback that you would like to share?

The main themes from peer reviewer feedback are summarized below.

### F2 – Peer reviewers agreed with participants’ examples of uses/users of health data that are WITHIN and NOT WITHIN social licence

* All peer reviewers agreed with the participants’ three examples of uses/users of health data that HAVE social licence; however, some reviewers identified additional safeguards that they would want in place (e.g., one peer reviewer indicated that there should be a declaration of conflict of interest for university-based researchers regarding their relationships with industry or other private/commercial stakeholders).
* All peer reviewers agreed with the two examples of uses/users of health data that are NOT WITHIN social licence
* As was the case with participants, different peer reviewers had different views on whether (i) private sector uses and (ii) researchers using data about historically marginalized populations COULD BE WITHIN social licence. Some peer reviewers supported either or both of these under specific conditions, others did not.

### F3 – Peer reviewer comments about participants’ requirements for health data social licence

Like participants, some peer reviewers had distinct and personal views about unique essential requirements for health data social licence. In some cases, peer reviewers suggested that the requirement in Appendix C be modified, in other cases they suggested new requirements.

Examples of peer reviewer suggestions for new or modified essential requirements include:

* Researchers (not just patients) should be able to access data in a timely manner
* The private sector should only be able to access health data in cases where the public or academic partners receive at least 50% of monetary benefits
* Data shouldn’t be anonymized because that would prevent analyses of the social determinants of health
* Any leader involved in governing health data should be qualified to manage this information and vetted properly, and should not necessarily be an elected official
* It is important that governance and decision-making bodies include patients and members of the public, but it is equally important that funding for these governance bodies be separated from politics and from the effects of lobbying
* Private companies are not monolithic and necessarily dangerous; one must see and create opportunities and be vigilant
* Systemically marginalized populations may need an ombudsman/navigator as they cannot always exert control over how their data are used, shared and re-used
* The complaint process available to people in cases where they believe the use, sharing, or re-use of their health data violates legislation or the consent that they have provided must be accessible for people with and without digital literacy and with and without disabilities

### F4 – Peer reviewer comments on the process

One peer reviewer questioned the inclusive design process and argued against giving attention to suggestions that came from just one person.

### F5 – Peer reviewer comments on limitations, unanswered questions, and future work

* Some peer reviewers agreed that non-expert advisors should be involved in future public engagement, and emphasized that education and data literacy are also needed
* Some peer reviewers felt that, going forward, the goal should not be to strive for consensus, because there will always be dissenting opinions about acceptable uses and users of health data
* Different peer reviewers had different views about how prescriptive and specific the report should be regarding future work and unanswered questions
* Some peer reviewers suggested additional unanswered questions, for example:
  + “Is there a distinction in social licence when it comes to companies that are funded by governments through our publicly funded healthcare systems versus those that are not?”
  + “Who counts as a healthcare provider when data are shared among healthcare teams – are all healthcare providers able to access and use all of the data?”
  + “Would outcome-based performance and accountability agreements with publicly funded private corporations make a difference in social licence/people’s levels of trust?”
* Peer reviewers also suggested that the definitions of key concepts be expanded upon and/or included in the report. Their suggestions included:
  + Increase the examples under the definition of health data (e.g., include elements of real-world data, say something about evidence quality through the prescription drug product life cycle)
  + Define historically marginalized populations
  + Define what constitutes a public benefit from health data