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## Appendix B: Process

### B1 – Recruitment

In November 2021, HDRN Canada and GRIIS launched recruitment for the project with an email communication. Because previous studies have indicated that health data sharing, linkage, and access is a complex and poorly understood topic, the email was sent to networks and groups on individuals that already have some knowledge of health data uses through their roles on patient, public, or community advisory groups.

Following a review of applications and confirmation of experience with external references, 23 people from across Canada were offered roles as English or French participants, 20 of whom were able to participate in all meetings and steps to create the report. Participant selection focused on maximizing the diversity of participants across a range of factors including but not limited to age, gender, geography, and prior experience providing advice related to health data. Qualified applicants who were not selected to be participants were offered roles as peer reviewers.

Participants were provided an honorarium of $100 Canadian, paid in two installments at the beginning and end of the process.

### B2 – Pre-meeting work for participants

To support the report development process and prompt participant thinking, HDRN Canada and GRIIS team members developed a table of requirements for health data social licence that had been identified by previous groups and studies focused on public and patient views about health data (see Appendix C). Before it was presented to participants, the table was refined with input from the HDRN Canada Public Engagement Working Group and external advisors.

The table uses the language “IT IS IMPORTANT THAT…” to be inclusive of the different ways that a requirement might be expressed. For example, “IT IS IMPORTANT THAT: the privacy of people who contribute health data is protected” is intended to be a general version of statements like “I expect my privacy to be protected”, “I have a right to privacy”, “Use of health data is conditional on my privacy being protected” and “Data holders have an obligation to protect privacy.”

In March 2022, individuals who were selected to be English or French participants were asked to submit a document with information about what they perceive to be essential requirements for health data social licence, and their reasons for identifying those requirements. Participants were asked to consider the table of requirements (Appendix C) but not feel limited or constrained by the requirements in the table in any way. Participants were also asked to provide one or more examples of health data uses/users that (i) are WITHIN social licence, (ii) are NOT WITHIN social licence and (iii) COULD BE WITHIN social licence with additional conditions, safeguards and/or protective measures in place.

Throughout the process, approximately three quarters of the requirements for health data social licence that were submitted by participants were expressed in participants’ own words as opposed to the language in the table in Appendix C. In those cases, representatives from HDRN Canada and GRIIS mapped the participants’ input to existing requirements where possible, and/or edited or created requirements to capture participants’ views. In all cases the accuracy of the mapping or new requirement language was confirmed with the submitter.

In cases where a participant wanted edits that would change the scope or meaning of a requirement that other participants had already selected, we created a second requirement rather than assume that everyone agreed with the wording change(s). As a result, there are four pairs of requirements that have similar wording.7

### B3 – Participant dialogue focused on essential requirements

On March 28, 2022, HDRN Canada and GRIIS held one 2-hour meeting of the English participants immediately followed by a 2-hour meeting of the French participants focused on participant dialogue about essential requirements for social licence.

Participants were encouraged to speak in support of requirements that they felt were essential and to question requirements that they did not agree with. Time was allocated to ensure that there was discussion of requirements that many participants perceived to be essential, and requirements that only one person perceived to be essential.

### B4 – Opportunity for participants to change their written submissions

After the March meeting, participants were provided with the opportunity to revise the information that they had submitted previously. Nine of the 20 participants made changes. Participants were also asked to review and provide feedback on definitions of health data and social licence to be included in the final report.

### B5 – Participant dialogue focused on uses/users within and outside of social licence

On April 25, 2022, HDRN Canada and GRIIS held separate 2-hour meetings with the English and French participants to determine whether there was consensus about whether specific examples of health data uses and users were WITHIN social licence, were NOT WITHIN social licence, or COULD BE WITHIN social licence. The examples for discussion were selected as ones that participants might be able to come to consensus on based on participants’ previous written and oral advice (e.g., no examples were presented that previous conversations had indicated participants had irreconcilable views about).

HDRN Canada and GRIIS used “five finger” facilitation to help participants determine how close participants were to consensus. According to this method, five fingers (an open hand) represent complete support and zero fingers (a fist) represents opposition.

7 For example, there was not agreement about how quickly people should be able to access their own health data so Appendix C includes two similar requirements

E6: “*People (and caregivers they authorize) can easily access health data […] in a timely manner […]”*and

E7: “*People (and caregivers they authorize) can easily access health data […] in real-time […]”*

Each discussion item started with the presentation of a statement and participants communicated their initial level of support on video using the number of fingers or via direct message to the facilitator. One or two people who strongly supported the statement were asked to speak about the reasons for their support, and people who opposed the statement were offered the opportunity to speak. In several cases, this led to wording changes to the statement. After the discussion, people communicated their support or opposition to the statement a second time using the “five finger” method, providing them with an opportunity to change the number of fingers they communicated the first time.

Consensus was deemed to have been achieved in cases where all participants communicated one or more fingers of support. In some cases, the “five finger” method was combined with polling to gather additional information about the conditions and protections participants felt were essential to be in place for them to be in agreement with the example. The practicalities of having different meetings with English and French participants necessitated email follow up with participants, e.g., checking in with participants of the English meeting about wording changes proposed by participants of the French meeting which occurred later on the same day.

### B6 – Preparation of the report

From May to July 2022, the results of the two meetings and written submissions were converted into a draft report that was reviewed and refined by participants.

After edits had been made in response to participants’ feedback the updated draft report was reviewed by 13 peer reviewers in August 2022 (see Appendix F).

The report was finalized and made public in French and English in September 2022.

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