

International Journal of Population Data Science

Journal Website: www.ijpds.org



Swansea University
Prifysgol Abertawe

Health data social licence: An inclusive process to learn more about the perspectives of experienced public and patient advisors

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Submission History

Submitted:	19/01/2024
Accepted:	14/03/2024
Published:	16/04/2024

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Abstract

The term “social licence” has been used to describe which uses and users of health data the public supports – and under what conditions. From November 2022 to January 2023, Health Data Research Network Canada was funded by the Public Health Agency of Canada to explore whether there was consensus among experienced public and patient advisors on: (i) uses of health data that all members supported or opposed and (ii) what constitutes an essential requirement for a health data use or user to be within social licence.

The project was conducted in English and French in collaboration with the Interdisciplinary Research Group in Health Informatics (GRIIS) at the University of Sherbrooke. It involved 20 public/patient advisor “participants” and an additional 13 public/patient advisors who served as peer-reviewers, all of whom had prior experience working in a health-related field and/or with health data. The process followed inclusive design principles in that it captured views held by the majority and minority of participants, including views expressed by only one or two participants.

After two 2-hour facilitated sessions, participants agreed that it is within social licence for health data to be used (i) by healthcare practitioners to improve patient care, (ii) by governments and administrators to improve the health system, and (iii) by university-based researchers to understand disease and well-being. There was consensus opposition to (i) an individual or organisation selling someone else’s identified health data and (ii) health data being used for a purpose that has no public or societal benefit. There was no consensus about what constitutes an essential requirement for a use or users of health data to be with social licence. The results of the process have been published in a non-peer-reviewed report co-authored with participants.

This paper has been co-authored with a subset of the participants and peer-reviewers to present a high-level summary of the findings, methodological details, and templates to enable other groups to adapt the process to their own settings. It also presents the results of an anonymous evaluation of the process using the Public and Patient Engagement Evaluation Tool (PPEET), which were mostly positive and identified some areas for improvement.

Keywords

public engagement; data governance; health data social licence; administrative data; inclusive design

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Introduction

There is growing recognition that significant public benefits could be realised through increased health data sharing, linkage, and access [1–5]. Though privacy and data protection continue to be a strong focus of laws, policies and agreed best practices for health data, other considerations are being brought into the dialogue including: the human right to share in scientific advancement and its benefits under Article 27 of the Universal Declaration of Human Rights [6], the importance of self-determination and autonomy for people whose data are used [7–9], the implications for individuals and society when health data are underutilised [10, 11], and the need to increase equity in health data collection and use [12–17].

Studies conducted in multiple countries, including Canada [18], the US [19], Australia [20] and the UK [21], have found that many members of the public see data as an asset that should be used for public benefit provided that risks are addressed and specific conditions (such as those related to privacy/security, commercial motives, equity and fairness) are met [7, 22–28]. There is also growing recognition that the best policies and practices related to health data are those that are co-developed with patients and members of the public [8, 28–32].

A social licence to operate is an informal agreement that is granted by communities and stakeholders for organisations to perform certain kinds of work. Increasingly, the term “health data social licence” is being used to describe which data-related activities members of the public support, and under what conditions [18, 33]. For example, the use of patient data for commercial and profit purposes is considered to be outside of social licence by some people based on multiple studies that identify it as problematic [18, 21, 22, 24, 27, 34].

To inform the work of the *Pan-Canadian Health Data Strategy* [35], Health Data Research Network Canada (HDRN Canada) was contracted by the Public Health Agency of Canada to work with the Groupe de recherche interdisciplinaire en informatique de la santé (GRIIS) to design and implement a process to explore public perspectives on acceptable uses and users of health data. In contrast with previous research that has focused on understanding how patients and members of the public perceive health data uses, often through focus groups or citizens juries, we sought to identify areas of consensus support and consensus opposition among experienced public/patient advisors living in Canada. Specifically, the aim was to learn more about particular examples of uses and users of health data that members of the public living in Canada supported or opposed, and also learn about the requirements, conditions and safeguards (referred to as “requirements” going forward) that participants viewed as essential for a use of health data to be within social licence.

A non-peer-reviewed report with the results of our process has been published on the Health Data Research Network Canada website (available at: <https://www.hdrn.ca/en/public/public-resources/reports/social-licence-report/>) and the results were published in a plain language article in *The Conversation* which has been viewed more than 4500 times since January 2023 [36].

This paper has been co-written with a subset of the people involved in our process to communicate findings to a broader audience of scholars and health data practitioners

and to provide details so that other groups can replicate the process in their own settings. We also present the results of an anonymous evaluation of our process conducted using the Public and Patient Engagement Evaluation Tool (PPEET) developed by McMaster University.

Methods

Team

Research team members: The work was led by JB, PAP, AC and RD as part of their contributions to the public engagement work of Health Data Research Network Canada (HDRN Canada).

Public/patient participants: A total of 20 Canadian participants (10 English speaking and 10 French speaking) took part in the process (Table 1 – inline). Previous studies have reported that health data sharing, linkage, use, and reuse is a complex topic that is not well understood by members of the general public [18, 34]. Therefore, recruitment focused exclusively on people who had prior experience as public or patient advisors in a health-related field and/or working with health data, e.g., in community organisations, hospitals, or health research institutes with the hope that such participants would be well-positioned to engage in dialogue with each other without extensive pre-reading or background preparation. Snowball recruitment was conducted beginning with emails sent to Canadian public or patient organisations and advisors by PAP, AC, RD. Participant selection focused on maximizing the diversity of participants across a range of factors including, but not limited to age, gender identity, highest education level, geography, ethnicity, and prior experience or advocacy positions. Participants were provided an honorarium of \$100 Canadian, paid in two installments at the beginning and end of the process.

Public/patient peer-reviewers: Thirteen qualified applicants (eight English speaking, five French speaking) who were not selected to be participants were offered roles as peer reviewers for the report (Supplementary Material 1– Characteristics of peer reviewers). Peer reviewers were provided an honorarium of \$25 Canadian, paid after they reviewed and provided comments on the draft report.

Study design

Participants were content creators and co-authors as opposed to being the objects of a study [37]. The process was facilitated by research team members employed by HDRN Canada (PAP, JB) and GRIIS (AC, RD). Participants’ perspectives were captured using a combination of written submissions and oral input during facilitated dialogue sessions. For written input (see Supplementary Material 2 – Step 1 document) participants were given flexibility regarding timelines and the format in which feedback was received. Participants also had the opportunity to change their written input at multiple points during the process.

Separate dialogues were held in English (morning) and French (afternoon) on the same dates. In the dialogues, a modified version of the “fist to five method” [38] was used instead of binary yes/no voting to determine if participants

Table 1: Characteristics of participants in the process to learn more about health data social licence (N = 20)

Variable	Percent	Frequency
First language		
English	45	9
French	45	9
Dutch	5	1
Spanish	5	1
Language of participation		
English	50	10
French	50	10
Age		
65–84	45	9
45–64	25	5
35–44	25	5
25–34	5	1
Gender identity		
Man	50	10
Woman	50	10
Other gender or prefer not to say	0	0
Highest Level of Education		
Graduate degree	60	12
Post-secondary degree or certificate	35	7
Some post-secondary education	5	1
High school (only)	0	0
Optional self-identified ethnicity or ancestry*		
No response	30	6
Francophone	20	4
Belgian	10	2
White	10	2
Black and African	5	1
East Indian	5	1
European/white	5	1
First Nations	5	1
Korean Canadian	5	1
Spanish	5	1

*Applicants were asked the following **optional** question about their ethnicity or ancestry “As we are committed to hearing from people with diverse experiences and perspectives, if comfortable, please self-describe your ethnocultural background”.

Participants noted their primary residence as being in the following provinces/territories: Newfoundland and Labrador (N = 1), Nova Scotia (N = 2), PEI (N = 1), Quebec (N = 11), Ontario (N = 2), Manitoba (N = 1), Alberta (N = 1), and British Columbia (N = 1).

were close to agreement on a topic [39]. This entailed asking participants to indicate their “fingers” of support at the beginning and end of discussions about statements focused on various uses of health data. The “fingers” of support method created space for people in the minority to express their views by (i) providing a simple mechanism for people to signal disagreement or concern with majority views, and (ii) identifying people whom the facilitator should invite to contribute to speak to ensure that the full range of supportive and non-supportive views were expressed. The “fingers” of support displayed at the end of each discussion allowed the facilitator to determine whether there was a consensus regarding support or opposition to a use of health data (i.e., all participants displayed one or more fingers of support for

a statement) or no consensus (i.e., any participant displayed a fist indicating opposition to the statement). The study followed inclusive design principles [16] and had the explicit aim to capture all participants’ views, including those held by a minority of participants.

Setting and process

Data were collected and analyzed in iterations according to the following process:

1. The 20 participants were provided background material prior to the beginning of the process in their preferred language of English or French, including a plain

language background and template to provide written comments. The backgrounder briefly summarised the findings of previous research, and explained the aim, time commitment and honorarium for the project. The template included a list of 40 essential requirements for health data social licence prepared by the HDRN Canada Public Engagement Working Group based on the literature and some external advice (Supplementary Material 2 - Step 1 document). Using this template, participants were asked to submit:

- Examples of uses of health data that are WITHIN social licence from their perspective.
 - Examples of uses of health data that are NOT WITHIN social licence from their perspective.
 - Essential requirements for a use of health data to be within social licence, informed, but not constrained by, the list of potential requirements for health data social licence.
2. Written submissions were analyzed by AP, JB, RD and AC to map participants' input to existing requirements (if not already in the language in the requirements table), and/or existing requirements were edited or new requirements were created to capture participants' views.
 3. Two 2-hour virtual facilitated dialogue sessions (one in English, one in French) to present the compilation of all participants' requirements from Step 1 and explore whether there was consensus about a subset of requirements that were perceived to be essential. Participants were also encouraged to ask questions and provided advice on the process and report contents and format.
 4. Participants were provided with the opportunity to change their written submissions from Step 1 in response to what they had learned and heard at the first dialogue session. Twelve of 20 participants made at least one change, usually adding an essential requirement that another participant had suggested.
 5. Two 2-hour virtual facilitated dialogue sessions (one in English, one in French) to see if there was any consensus about specific uses of health data being WITHIN or NOT WITHIN social licence based on the number of "fingers" of support assigned by participants.
 6. Email and online collaboration to convert the process outputs into a draft report, which was refined by participants, provided to peer reviewers for comment, then published on the HDRN Canada website [40].
 7. Anonymous evaluation of the process using the Public and Patient Engagement Evaluation Tool (PPEET) [41] developed by McMaster University, with small modifications to increase its applicability the engagement (Supplementary Material 3).

Additional details on the process can be found in Appendix B of the public report for the project [39].

Patient and public involvement

Experienced patient and public advisors served as co-authors and peer reviewers for the report, *Social Licence for uses of Health Data: A report on public perspectives*, published on the HDRN Canada website [40]. Twelve of the experienced public/patient advisors (six participants and six peer reviewers who were part of the process) are also co-authors of this publication.

Results

Outputs and findings of the process

In brief, there was consensus support among participants for three uses of health data and consensus opposition to two uses of health data (see Text Box 1). Peer reviewers did not express disagreement with the consensus views of participants.

There was no consensus among participants about what constitutes an essential requirement for health data social licence. The original list of 40 potential requirements provided to participants in the first step of the process grew to include 85 requirements in seven categories by the end of the process (see Box 2 and Appendix C of the report [42]). Some requirements were supported by many people, others were seen as essential by just one or two participants. Out of the 85 requirements, 38 were perceived to be essential by just one participant.

Participant and peer reviewer evaluation of process

Of the 20 participants, 15 people (four English speaking and seven French speaking participants, two English speaking and two French speaking peer reviewers) anonymously evaluated the process using the PPEET (Table 2 – inline, Supplementary Material 4 for peer reviewer results). Peer reviewers are not included in the main table because they had much less involvement throughout the process (about one to two hours of work total) compared to participants, who spent four hours in dialogue with each other, as well as time spent on independent reflection.

Discussion

Process outputs and findings

Overall, the participants and peer reviewers supported health data being used for public benefit, provided that their concerns were addressed. These findings are consistent with previous Canadian and international studies that have found conditional public support and social licence for uses of health data that produce public benefits [18–28].

In particular, the requirement categories identified by participants (Box 2), were similar to key themes identified in the Aitken *et al.* systematic review of qualitative studies [24] that examined public attitudes towards sharing or linking health data. Furthermore, there were no themes identified in the systematic review that were contrary to the perspectives of participants in our process. In addition, our process also

1. Healthcare practitioners to directly improve the healthcare decisions and services provided to a patient.
2. Governments, healthcare facilities, or health systems administrators to understand and improve health care and the healthcare system.
3. University-based researchers to understand the drivers of disease and wellbeing.

4. Someone or some organisation to sell (or re-sell) someone else's identified health data.
5. Health data to be used for a purpose that has no patient, public, or societal benefit.

Box 2: Requirement categories identified by participants (in alphabetical order)

- A: Benefits
- B: Commercial Organisations
- C: Equity and Fairness
- D: Governance and Oversight
- E: Personal Control and Involvement
- F: Privacy and Security
- G: Transparency, Communications and Data Literacy

Table 2: Participant responses to the modified Public and Patient Engagement Evaluation Tool (N = 11)

Strongly agree		A : Communications and supports for participants B : Sharing your views and perspectives C : Impacts and influence of the project D : Final thoughts
Agree		
Neither agree nor disagree		
Disagree		
Strongly disagree*		
Did not answer	X	

*There were no “strongly disagree” responses from participants

[illegible]

held by a minority of participants as opposed to allowing them to be out-voted or hidden. For example, two of 20 participants thought it was essential that data collectors “mitigate the

risk that patients (who are often in a vulnerable state) feel pressured to provide consent” for secondary uses of their data. Another example of a requirement expressed by a minority of participants was two participants’ view that it is essential that “Unless there is expressed consent for data sharing outside of Canada, health data are stored in Canadian jurisdictions and stay within Canadian law.” Other unique requirements highlighted by participants in our process included the role of accountable governance bodies in enforcing consequences for data theft and fraud, and the importance of access to personal health data in a useable and timely (or even real-time) manner.

The process of involving participants and peer reviewers as co-authors afforded them the opportunity to provide additional reflection on the process and findings presented in the non-peer reviewed report for the work [40]. For example, one co-author noted the importance of finding a balance between the sensitivity of health data that requires special data protection measures, and the effective use of health data to improve patient care and advancing research. Another co-author emphasised requirements related to equity and fairness, particularly around the importance of Indigenous data sovereignty and ensuring that people who contribute health data, especially those from marginalised and/or colonised populations, are not exploited. Another public/patient co-author noted the strong view among members of the public that they should have access to their health data and a say in determining how data are used with a focus on ensuring that individuals understand the potential risks inherent in sharing their data.

To our knowledge, the work presented here is unique among studies of public perceptions related to health data in its incorporation of inclusive design principles to capture views held by a minority of participants and points of disagreement [16]. As noted by Treviranus, the views of people in the minority are important because those people are often not well served by the *status quo*, and they may hold knowledge and innovative ideas that are essential to the design of processes, policies and products that work for the entire population, not just the majority. Therefore, while our sample size of 20 participants is small, we feel that publishing and highlighting views held by a minority of participants is an important step toward identifying more and different perspectives about health data social licence.

Our process also captured requirements that participants actively disagreed about. For instance, four of 20 participants believed it was essential that “Opt-in consent is obtained before health data are collected, used, shared, or re-used (i.e. people agree in writing to the use(s)/user(s) of their data)”. However, one participant disagreed because, from their perspective, “Too much protection, for example a regime that requires consent for each project (opt-in), can make research much more complicated if not impossible.”

Another point of disagreement related to patients’ access to their own data. Eight participants indicated that it is essential that “People (and caregivers that they authorise) can easily access health data that have been compiled about them in a usable format (e.g., one that can be read by a computer or electronic device) and in a timely manner so that they can make informed decisions about their health and health care.” However, one participant disagreed because, from their perspective “The security issue of individuals being able to

access their health data is far too high and can jeopardise the privacy of individuals.”

There was no agreement among the 20 participants regarding (i) use of health data by companies and (ii) use of health data from or about systematically marginalised populations. Most participants supported both of those uses if specific conditions and safeguards are put in place; others were skeptical about whether safeguards and conditions could be operationalised and concerned that if harms were done by companies and/or to historically marginalised communities, they could not be undone.

Considered together, the outputs of the process suggest that there is no definable boundary when it comes to social licence for uses of health data because, even among the small number of participants in our process, there were divergent views regarding which users and users of health data should be allowed and prohibited. From this we infer that expansive plans to increase use, sharing and re-use of health data are likely to be opposed by some groups, no matter what requirements, conditions and safeguards are put in place.

On the other hand, the outputs of our process suggest that there may be agreement on a “centre” of social licence, which can be defined in terms of uses of health data that are likely to be supported by members of the public. We note that focusing initiatives, policies and processes related to health data on the three uses that participants of this process supported (Box 1) could yield many benefits including: better patient care, better health system planning, and better understanding of disease and wellness. We suggest that these and other benefits could be realised if there is a concerted and continuous effort to identify and act on increasing the health data uses and users that members of the public support.

Participant and peer reviewer evaluation of the process

Overall, the 11 anonymous responses to the PPEET were positive (see Table 2 for participants’ responses, Box 1 for example comments and Supplementary Material 4 for peer-reviewers’ responses). For instance, only one person who completed the evaluation selected the “strongly disagree” response for any of the 16 positively-worded statements of the PPEET questionnaire. The involvement of participants and peer reviewers as co-authors in this paper confirmed the generally positive assessment of the process. For example, four out of 11 participants indicated that they learned from the process, and five participants appreciated the inclusive design and variety of perspectives that were heard, including voices in the minority. Box 3 includes some example of anonymous comments captured in the PPEET selected by the public/patient co-authors of this paper.

Participants and peer reviewers were most likely to select “Disagree” or “Neither Agree nor Disagree” to PPEET statements related to the impacts and influence of the engagement. For example, three out of 11 participants who completed the evaluation selected “disagree” or “neither agree or disagree” for the statement “I am confident the input provided through this initiative will be used by HDRN Canada, GRIIS and other organisations engaging with the public about health data”. This more negative to neutral impression of the

Box 3: Examples of *verbatim* participants' comments in the PPEET questionnaire

"The authors made a genuine effort to ensure all points of views were relevant, even if these points did not represent the majority. That was quite appreciated."

"I hope it will spur further discussion about aspects influencing social licence and that it also provides rationale to fund future projects to better understand public points of view regarding health data."

"The concept of social acceptability (social licence) was interpreted differently by different participants. Some took a very personal perspective (is this acceptable for me?), while others, including myself, asked how the general population would accept data sharing." (French response translated into English)

"Establish systematic mechanisms to monitor the impact of the report." (French response translated into English)

"This was a very wide-ranging, comprehensive discussion. I had already taken part in this kind of discussion through various projects, but this one made me think of situations or perspectives I hadn't thought about before." (French response translated into English)

impact of the engagement was also reflected in respondent comments. Three of 11 participants wanted to know more about the report's intended audience and use(s) and were hopeful that the findings would contribute to future work in the area of health data social licence, whereas two participants were not confident that the report would be shared widely or used at all.

Most of participants' suggestions for process improvement focused on how the dialogues were conducted. Two participants suggested conducting mixed dialogue sessions with English and French participants together (as opposed to separate English and French dialogue sessions). Four participants suggested the addition of more meetings and/or face-to-face meetings and wanted the facilitators to intervene more so that no individuals dominated the dialogue, and everyone had a chance to speak. For example, one participant noted "I often felt like there wasn't enough time, sometimes because one person spoke up repeatedly or took a lot of time to talk, and not always in line with the topic. . .". A co-author involved in the writing of this paper elaborated on this point, noting that, while the process seemed very democratic, some of the "bolder participants got more airtime."

In terms of other areas for improvement, some participants commented that there should have been more time for discussion, and one person associated the overall shortage of time with the fact that significant time was allocated to the discussion of views held by a minority of participants.

The research team had hypothesised that peer reviewers might have a less positive perception of the process because (i) they were less involved in the work than participants and (ii) the final report did not reflect their views to the same extent as it presented participants' views. However, peer reviewers' assessment of the process was similar to that of participants. For example, across the four peer reviewer respondents to the PPEET, only one "strongly disagree" response was received for the 16 positively-worded PPEET statements, and that response was for the PPEET statement "The individuals participating in the project represented a broad range of perspectives on the topic" (potentially related to the fact that peer reviewers had no visibility on the characteristics of other reviewers or participants). Overall, the peer reviewer PPEET responses suggest that members of the public can have positive views of processes even when they have small roles if there is clarity regarding their contributions and compensation from the outset.

Limitations and future work

This work has various limitations. Foremost, the participants and peer reviewers were experienced Canadian patient and public advisors who are more likely to have knowledge of the benefits, risks, and opportunities associated with data use, sharing, and re-use than other members of the public. Further, participants were generally highly educated (the majority with at least post-secondary education) and older (all but one of the participants was over the age of 35). For these reasons, their perspectives may be different from people with no prior exposure to the topic of health data and from people who are younger, have less formal education, or are members of different ethnocultural groups. It is also possible that the examples of health data uses that participants perceived to be within social licence would be perceived as being outside of social licence by other people, and that there are other uses of health data that are within social licence that were not identified by the participants of our process. It is possible that repeating our process with a different group of people and/or with additional time for dialogue would result in different (and possibly contrary) results. In addition, while participants in our process were not asked to read the systematic review by Aitken *et al.* (2016) [24], the original list of 7 requirement categories supplied to participants in Step 1 of the process was informed by the Aitken review, which could account for some of the consistency between our findings and the Aitken review.

Though participants discussed the needs and interests of historically colonised and/or marginalised populations, additional work would need to be undertaken to understand health data social licence from the perspective of people and groups that are different from mainstream society because of their ethnicity, abilities, language, gender, and other characteristics. Further, while the participant group included one person who is First Nations, and other people who were not Indigenous that emphasised the importance of Indigenous rights, separate Indigenous-led work would be required to identify the perspectives and concerns of First Nations, Inuit, Métis Peoples and other Indigenous peoples.

The facilitated process and dialogue between participants generated many unanswered questions that would require future work and definition. For example, questions were raised about the practical meaning of certain words or phrases related to health data social licence including what constitutes, "legitimate" uses of health data, or data accessed in a "timely manner".

Given the small number of people who completed the PPEET, it is possible that the results do not present a complete picture of participants and peer reviewers' views.

Conclusions

Twenty experienced Canadian patient and public advisors agreed on three uses of health data that were supported and two uses of health data that were opposed. There was no agreement about what constitutes an essential requirement for health data social licence. An evaluation of the process that was used to learn about participants' views using the PPEET indicated that the process was perceived favourably and identified some areas for improvement.

This work is intended to be an input for future and ongoing public involvement and engagement initiatives concerning health data social licence. By including detailed methodology and published templates that can be replicated or adapted, we provide a blueprint for researchers and other stakeholders to engage with members of the public who have different perspectives, including people who do not have prior experience related to health data and people from historically colonised and/or marginalised populations.

Acknowledgments

The authors would like to thank members of the Health Data Research Network Canada Public Engagement Working Group who co-developed the initial list of requirements for health data social licence and provided advice on the process: Jean-François Ethier, Frank Gavin, Kimberlyn McGrail, Jenine Paul, Catherine Street and Jannath Naveed. We also thank Kwame McKenzie, CEO of the Wellesley Institute, who provided advice on the initial list of requirements for health data social licence. In addition to the public/patient co-authors on this manuscript, we would also like to thank the other public/patient advisors who participated in the process: Christian Blouin, Carrie Costello, Martin Dawes, Marc Desrosiers, Annie-Danielle Grenier, Alies Maybee, Shirley Morrison, Shaneel Pathak, Robert Olivier, Juanna Ricketts, Ginette Saucier, Ilse Tack, Eva Villalba, Raymond Vles, Mike Warren, Collette Bérubé, Maggie Keresteci, Rhonda Massad, Annie Poirier, Luc Ricard and Maureen Smith.

This work was funded by the Public Health Agency of Canada to support the development of the *Pan-Canadian Health Data Strategy*, as well as in-kind contributions from team members' employer organisations. The analyses, conclusions, and statements expressed in the report are those of the authors, and not necessarily those of the Public Health Agency of Canada.

Statements of conflicts of interest

No conflicts to declare.

Ethics statement

This study did not require ethical approval as it did not involve human participants as research subjects or the use of personal data.

Data availability

All data relevant to the study are included in this paper or in its Supplemental Material.

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Abbreviations

PPEET: Public and Patient Engagement Evaluation Tool
HDRN: Canada Health Data Research Network Canada
GRIIS: Groupe de recherche interdisciplinaire en informatique de la santé

Supplementary Material

Supplementary Material 1: Characteristics of peer reviewers (N = 13)

Variable	Percent	Frequency
Total		
First language		
English	62	8
French	38	5
Language of participation		
English	62	8
French	38	5
Age		
65-84	38	5
45-64	46	6
35-44	15	2
25-34	0	0
Gender identity		
Woman	85	11
Man	15	2
Other gender or prefer not to say	0	0
Education		
Graduate degree	85	11
Some post-secondary education	7.5	1
High school (only)	7.5	1
Post-secondary degree or certificate	0	0
Optional self-identified ethnicity or ancestry*		
Caucasian	31	4
No response	31	4
Francophone	15	2
Mixed	15	2
Southeast Asian	8	1

*Applicants were asked the following **optional** question about their ethnicity or ancestry: As we are committed to hearing from people with diverse experiences and perspectives, if comfortable, please self-describe your ethnocultural background. Participants noted their primary residence as being in the following provinces/territories: Newfoundland and Labrador (N = 1), Quebec (N = 6) and Ontario (N = 6).



Supplementary Material 2. Step 1 document: Participant team members' perspectives on four topics related to social licence for health data uses and users

Note: Previously referred to as the "Health Data Social Licence White Paper" project, the term "White Paper" was removed in final outputs based on feedback from participants that people may mistakenly associate the work with the 1969 federal government White Paper on Indigenous rights.

STEP 1 – PARTICIPANT TEAM MEMBERS' PERSPECTIVES ON FOUR TOPICS RELATED TO SOCIAL LICENCE FOR HEALTH DATA USES AND USERS

Thank you for completing the four sections of this Step 1 document and returning it to Alison Paprica by March 11, 2022. Please review the Appendix at the back of this document before you email your completed document.

Your name: _____

1. Essential requirements for a health data use and/or user to have social licence from your perspective

Please tell us at least three things that you believe are essential for social licence for health data and one or two sentences about why each is essential from your perspective. The table below asks for 3-5 suggestions because we are hoping that participant team members will reflect on and prioritize the requirements that are most important to them. However, you are not limited to five requirements and can add as many additional rows to the table as you like.

At the back of this document, we have included a summary table of public and patient expectations, rights, conditions, and obligations related to health data. This table is based on work from other groups and previous studies. We have included this information so that your responses can be informed by work that has been done in the past; however, the previous work should not limit or constrain your responses. We want to know more about what you think, regardless of whether it aligns with the findings of previous work.

No.	Essential requirement from your perspective	Why this is essential
1		
2		
3		
4	Optional	Optional
5	Optional	Optional

Optional add more rows if there are more requirements that you believe are essential

2. Health data use and/or user that HAS social licence from your perspective

- Please provide one or more examples of health data being used in a way that you SUPPORT
- In one or two sentences, please briefly tell us why you SUPPORT the example(s)
- Tell us about any conditions, safeguards, and/or protective measures that think need to be in place for the example(s) you SUPPORT

3. Health data use and/or user that DOES NOT HAVE social licence from your perspective

- Please provide one or more examples of health data being used in a way that you DO NOT SUPPORT (no matter what conditions, safeguards or protective measures may be in place)
- In one or two sentences, please briefly tell us why you DO NOT SUPPORT the example(s)

4. Health data use and/or user that COULD HAVE social licence from your perspective but ONLY IF specific ADDITIONAL conditions, safeguards and/or protective measures are in place

- Please provide one or more examples of health data being used in a way that you COULD SUPPORT if there were additional conditions, safeguards, and/or protective measures
- In one or two sentences, please briefly tell us why you COULD SUPPORT the example(s)
- Tell us about the ADDITIONAL conditions, safeguards and/or protective measures (i.e., in addition to those described in 2c) that you think need to be in place for the example(s) you COULD SUPPORT

OPTIONAL – If there is any other advice that you would like to share with us at this time, please enter it here.

List of requirements for health data social licence from previous studies (see Appendix C)

APPENDIX – FINDINGS FROM PREVIOUS STUDIES AND PRIOR WORK THAT MAY BE RELEVANT

Below, we have compiled a table with alphabetically ordered findings from previous studies and prior work focused on public and patient perspectives about health data. This information is provided to help prompt participant team members' thinking. When completing the form on the preceding page, you should not feel limited or constrained by what is in the table. It is possible that the table unintentionally omits things that are important to you.

Please note that we have used the language "IT IS IMPORTANT THAT..." in an effort to be inclusive of the different ways that a requirement might be expressed. For example, we hope that the language "IT IS IMPORTANT THAT: the privacy of people who contribute health data is protected" would be interpreted as a generalized 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." Additionally, we have avoided using words like "must", "should", or "ought to" in the list. We want participants to choose their own words when completing section 1.

Requirement Category (in alphabetical order)	IT IS IMPORTANT THAT: (in alphabetical order)
A: Benefits	A1: Aggregate health data statistics (not individual data) are used, shared, and re-used widely. A2: Health data are used, shared, and re-used to enable breakthrough discoveries that wouldn't be possible if health data were not shared. A3: Health data use, sharing, and re-use for public benefit is encouraged ("data aren't wasted"). A4: Health data use, sharing, and re-use leads to benefits for communities, groups, subpopulations and/or society as whole. A5: Health data use, sharing, and re-use leads to benefits for the same people who contribute health data for a particular purpose.
B: Commercial Organizations	B1: Commercial organizations must meet or exceed a higher standard or threshold for public benefit from health data use, sharing or re-use compared to non-commercial organizations. B2: Health data are not sold. B3: People who contribute their health data are not exploited by commercial organizations. B4: There are additional safeguards, conditions, and protections when any commercial organization uses, shares, or re-uses health data. B5: There are additional safeguards, conditions, and protections when insurance companies use, share, or re-use health data. B6: There are additional safeguards, conditions, and protections when pharmaceutical companies use, share, or re-use health data.
C: Equity and Fairness	C1: Health data are not used in ways that create stigma or discriminate against groups. Health data for and about equity-seeking populations (for example data about people with disabilities), are only used, shared, or re-used for purposes that the intended beneficiaries support. C2: Indigenous data sovereignty and the right to Indigenous self-determination are acknowledged and respected. C3: Equity-seeking populations have control over how their data are used, shared, or re-used. C4: People who contribute their health data are not exploited by any organization or individual
D: Governance and Oversight	D1: Accountable governance bodies for health data are in place. D2: Health data are only used, shared, or re-used for purposes that are legitimate. D3: External third-party oversight is in place for health data (e.g., an Information and Privacy Commissioner). D4: Governance and decision-making bodies (e.g., Board of Directors) include patients and members of the public.

	D5: Health data are held by trustworthy organizations.
	D6: The intended beneficiaries are involved in decisions about how health data are used, shared, or re-used.
	D7: There is a complaint process that is 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.
	D8: There is formal notice about how health data will be processed, used, shared, or re-used before health data are collected.
E: Personal Control and Involvement	E1: Opt-in consent is obtained before health data are collected, used, shared, or re-used (i.e., people agree in writing to the use(s)/user(s) of their data). E2: Opt-out consent is obtained before health data are collected, used, shared, or re-used (i.e., people are provided with information about the proposed use(s)/user(s) and given the option of NOT having their data used). E3: People can access information that is stored about their consents for health data and modify or withdraw their consents. E4: People can correct inaccuracies in the health data that has been compiled about them. E5: People can obtain a usable of health data has been compiled about them copy (e.g., one that can be read by a computer or electronic device). E6: The contribution of health data is voluntary.
F: Privacy and Security	F1: Cybersecurity and other safeguards are in place to protect all health data, including de-identified data and anonymized data. F2: In certain circumstances (e.g., when data are no longer needed for the purpose for which they were collected) health data are erased or deleted if a data subject requests ("the right to be forgotten"). F3: The default practice is to remove the names of individuals and other identifying information about individual and communities from health datasets (except in cases where authorized individuals require identifying information in order to provide, or plan, healthcare services or in order to link datasets collected by different organizations). F4: The number of people who have access to identifying information is kept to a minimum. F5: The privacy of people who contribute health data is protected. F6: There are additional safeguards, conditions, and protections when genetic data are used, shared, or re-used. F7: There are safeguards to prevent re-identification.
G: Transparency	G1: There is a process for people to pose and get answers to their questions about how data are used, shared, or re-used by whom, and for what purposes. G2: There is transparent and plain language about when, how, why and with whom health data are used, shared, or re-used without the consent of the data subjects. G3: There is transparent and plain language about who has access to what data for what purposes.



Supplementary Material 3. Modified *public and patient engagement evaluation tool*

As a participant in the *Social Licence for Uses of Health Data* project, we are interested in your feedback about the process, which included:

- Filling out the step 1 and 3 documents
- Participating in the two dialogue sessions
- Reviewing the draft report

We would like to know what you think went well, and what could have been improved.

This questionnaire, called the *Public and Patient Engagement Evaluation Tool (PPEET)*, was developed by researchers at McMaster University. It includes 19 statements or questions – some questions ask you to rate your level of agreement in response to a statement and others ask for you to provide your comments and feedback. The questionnaire should take 15 minutes or less to complete unless you choose to provide long responses to the open-ended questions. You are encouraged to share your experiences and any information you feel is relevant and will help us to improve our engagement processes.

We appreciate your feedback. It is critical to helping us improve our engagement processes. Please be aware that we will not be asking for any demographic information and all of the information you do provide will be confidential. Should you have any questions about this questionnaire, please contact Julia Burt at juliaburt@mun.ca

Thank you for your participation!

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Part A **Communications and supports for participation**

Please indicate your level of agreement with each of the statements below.

Q3 I had a clear understanding of the purpose of the *Social Licence for Uses of Health Data* project.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q4 The supports I needed to participate were available (e.g., technological support)

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q5 I had enough information to contribute to the topic being discussed.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)



- ☐ Strongly agree (5)

Q6 [Optional] Is there anything else that you would like us to know about how your participation in the *Social Licence for Uses of Health Data* project was supported?

Part B Sharing your views and perspectives

Please indicate your level of agreement with each of the statements below.

Q7 I was able to express my views freely.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q8 I feel that my views were heard.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q9 A wide range of views on the topics discussed was shared.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q10 The individuals participating in the *Social Licence for Uses of Health Data* project represented a broad range of perspectives on the topic.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q11 [Optional] Is there anything else that you would like us to know about how you were able to share your views?

Part C Impacts and influence of the project

Please indicate your level of agreement with each of the statements below.

Q12 I think that the *Social Licence for Uses of Health Data* project achieved its objectives.



- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q13 I am confident the input provided through this initiative will be used by Health Data Research Network Canada (HDRN Canada), le Groupe de recherche interdisciplinaire en informatique de la santé (GRIIS) and other organizations engaging with the public about health data.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q14 I think the input provided through this activity will make a difference to the work of Health Data Research Network Canada (HDRN Canada), le Groupe de recherche interdisciplinaire en informatique de la santé (GRIIS) and other organizations engaging with the public about health data.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q15 [Optional] Is there anything else that you would like us to know about the influence you think the *Social Licence for Uses of Health Data* project will have?

Part D Final thoughts

Please indicate your level of agreement with each of the statements below.

Q16 As a result of my participation in the *Social Licence for Uses of Health Data* project, I am better informed about the concept of health data social licence, as well as the essential requirements that should be in place for health data social licence, according to members of the public.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q17 Overall, I was satisfied with this engagement initiative.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)



- ☐ Agree (4)
- ☐ Strongly agree (5)

Q18 This engagement initiative was a good use of my time.

- ☐ Strongly disagree (1)
- ☐ Disagree (2)
- ☐ Neither agree nor disagree (3)
- ☐ Agree (4)
- ☐ Strongly agree (5)

Q19 What were the strengths of the *Social Licence for Uses of Health Data* project?

Q20 What could have been improved about the *Social Licence for Uses of Health Data* project?

Q21 [Optional] Is there anything else that you would like us to know about your experience with the *Social Licence for Uses of Health Data* project?



