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## Appendix A: Principles and approach

* This report is intended to inform readers about the topic of health data social licence and to identify potential implications for ongoing and future work in this area
* Multiple research studies and reports have come to the same conclusion: many members of the public support health data being used, shared, and reused for public benefit, but only if their concerns related to privacy, commercial motives, equity and fairness are addressed.5
* Our aim was to complement and build upon the findings from prior studies and reports by adding:
  + Experienced public and patient advisors’ views about essential requirements for a use or user of health data to be within social licence
  + Specific examples of health data uses and users that participants agreed are within or outside of social licence
  + Attention to the views of individuals who have different needs and expectations than most other people (which may not have been captured in previous reports and studies that focused on identifying main themes and majority views)
* *Social licence for uses of health data: A report on public perspectives* presents the views of participants about requirements for health data social licence and examples of uses/users that are within or outside of social licence, NOT the views of the Health Data Research Network Canada (HDRN Canada) and GRIIS project team members
* The report presents participants’ views using the standardized language of the table in Appendix C as well as examples of input in participants’ own words
  + This was done so that the report identifies commonalities between views that are expressed in different ways
* The process followed inclusive design principles6 which explicitly acknowledge that people who hold minority views are the ones who are least likely to be well served by the status quo and are often the holders of knowledge that is essential to design processes, policies and products that work for the entire population, not just the majority
  + The report identifies, but not focus exclusively on, the views and requirements that were supported by many participants
  + Views and requirements that were only supported by one or two participants are also included in the report
  + During meetings, participants were asked to share their views, listen to each other, and be open to changing their minds so that the report would be more than a compilation of individual views, but facilitators also made it clear that no participant should feel pressured to change their mind

5 For example, see Aitken, M.et al. (2016), [*BMC Med Ethics,* 17, 73](https://doi.org/10.1186/s12910-016-0153-x); Cumyn, A. et al. (2021), [*Journal of Empirical Research on Human Research Ethics*, *16,* 165-178](https://journals.sagepub.com/doi/10.1177/1556264621992214); Paprica, PA et al. (2019). [*CMAJ Open* 7(1):E40-E46](https://www.cmajopen.ca/content/7/1/E40/tab-figures-data); Teng, J et al. (2019). [*Int J Popul Data Sci.* 7;4(1).](https://ijpds.org/article/view/1103)   
6 See Treviranus, J (2018) [Medium.com](http://www.Medium.com)