HDRN Canada

Public and Patient Engagement and Involvement Practices in Health Data

Selected Canadian and International Examples

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# Background

Health Data Research Network Canada (HDRN Canada) has been asked by the lead of the Pan-Canadian Health Data Strategy (PCHDS) *Trust and Literacy Working Group* to identify examples of public and patient engagement practices and literature that could inform future public and patient engagement associated with the PCHDS.

This document presents the top-of-mind examples and resources identified by members of the HDRN Canada Public Engagement Working Group in early March 2022. It does not constitute a complete environmental-scan. The document also includes, as an appendix, a brief summary of relevant literature on the topic of social license for health data uses and users which was prepared previously by HDRN Canada for the PCHDS Health Data Social License White Paper project.

It should be noted that most of the organizations and initiatives presented in this document are following the increasingly common practice of bringing together a group of diverse patients or members of the public to provide advice. However, no single group of advisors, no matter how diverse, can advise from the perspective of groups, communities, and subpopulations that have a special interest in, or would be affected by health data collection, use, or re-use. For a comprehensive approach to public engagement, it is recommended that the PCHDS complement any general committees or processes that are established with complementary public engagement and involvement that is targeted and tailored to the rights, needs, and interests of Indigenous Peoples, Black communities, people with disabilities, and others. The references in the appendix include some guidance for this kind of tailored and targeted engagement.

# Canadian practices and examples with brief descriptions

## Health Data Research Network Canada Public Advisory Council

The role of the HDRN Canada Public Advisory Council (PAC) is to: (i) Advise HDRN about its short-term, medium-term, and long-term priorities; (ii) Advise HDRN about how to inform the public about its achievements, challenges, and plans; (iii) Identify and discuss new kinds of data, especially “patient-generated data”; and (iv) Advise HDRN on how to go beyond the PAC and engage with, and take advice from, the public at large or particular “publics.” The PAC [Terms of Reference,](https://www.hdrn.ca/wp-content/uploads/PAC-Terms-of-Reference-1.docx) first PAC [Annual Report](https://www.hdrn.ca/wp-content/uploads/HDRN-Canada_PAC-Annual-Report-2022_2023-1.docx) and [biographies](https://www.hdrn.ca/en/public/pac) of the current 16 members are provided on the HDRN public website.

## ICES Public Advisory Council

A key area of ICES’ public engagement action plan, the [ICES Public Advisory Council (PAC)](https://www.ices.on.ca/About-ICES/Public-Engagement/Public-Advisory-Council) is made up of members of the public from across Ontario and guides ICES on what matters most to Ontarians for health data research. PAC members: (i) Discuss issues related to data and health data research; (ii) Share feedback on selected ICES activities and studies; (iii) Provide perspectives on new data opportunities and partnerships; (iv) Guide what research questions matter most to the public; and (v) Shape ICES public-facing content and public engagement activities. Details on the PAC’s membership, terms of reference, and governance within ICES are provided in the [article](https://ijpds.org/article/view/1364) *Public engagement can change your research, but how can it change your research institution? ICES Case Study.*

## Newfoundland and Labrador public engagement in association with Health Accord NL

The vision of [Health Accord Newfoundland and Labrador (HANL)](https://www.healthaccordnl.ca/) is improved health and health outcomes for Newfoundlanders and Labradorians through acceptance of and interventions in social determinants of health, and a higher quality health system that rebalances community, hospital and long-term care services. Consistent and transparent patient and public engagement is a key guiding principle for HANL, and over 30 [public town halls](https://healthaccordnl.ca/town-halls/), 49 special interest town halls and more than 400 stakeholder group meetings have been held to ensure feedback from the public is incorporated into HANL’s recommendations, including those focused on digital technology and data governance. A key *call to action* in HANL’s recently released [final report](https://healthaccordnl.ca/wp-content/uploads/2022/02/HANL_Report_Document_Web_modFeb28-2022.pdf) is to develop a holistic and integrated provincial data governance model including a strategy for how data will be used to improve the health and social systems of the province in a transparent and accountable manner (see page 214).

## Interdisciplinary Research Group In Health Informatics (GRIIS) / CLARET

[GRIIS](https://griis.ca/en/about/) aims to support health research and clinical practice by developing socio-technological approaches and training the next generation, thereby contributing to building an efficient, fair and citizen-centered learning health system. The [CLARET project](https://griis.ca/en/research/claret/) focuses on ‘meta consent’ of health data, where patients and the public consent to share their health data with multiple research projects simultaneously. One important benefit of meta-consent is that it allows citizens to play active roles within health research and clinical practice – helping them to understand how their health data is used and what research results are obtained from their data. As part of CLARET’s work, the team conducted [surveys](https://journals.sagepub.com/doi/10.1177/1556264621992214) and focus groups with Quebec citizens, researchers and other stakeholders to obtain their views on meta-consent and to assess the influence of participants’ literacy levels on these views.

## Population Data BC (PopData)

To help inform the development of practices around the use, access and application of data for research purposes, [PopData](https://www.popdata.bc.ca/) engaged the public in two [deliberative public engagement sessions](https://www.popdata.bc.ca/BCDataDeliberation). The goal of the sessions was for participants to collectively develop policy recommendations that reflect what is important to them in research data use. Participants were provided with a plain language [information booklet](https://www.popdata.bc.ca/sites/default/files/documents/projects/Public_Engagement/Public%20Deliberation%20Event%202019%20Booklet%20FINAL.pdf) prior to the events, giving them an overview on the collection of individual-level data, how technology is creating opportunities for research by generating new data, and the current legislation and policies that guide how data can be shared for research.

## Newfoundland and Labrador Centre for Health Information (NLCHI)

[NLCHI](https://www.nlchi.nl.ca/) co-hosted the Modern Consent Design Jam, the goal of which was to develop a modern real-time consent model to support patient access. Participants included researchers, patients, clinicians, computer programmers, privacy professionals, decision-makers and other stakeholders who came together to collaboratively address how to enable meaningful consent of health data through panel discussions and working tables focusing on various aspects of health data consent: Medical Care Plan (MCP) renewal, hospital kiosks, patient and researcher portals, point of care and mobile apps. NLCHI has also committed to strong citizen and provider engagement throughout their strategic priorities, including the development of a personal health record for all citizens of the province, as outlined in their [2020/2021 annual report](https://www.nlchi.nl.ca/images/2020-21_NLCHI_Annual_Report.pdf).

## SPOR Evidence Alliance

The [SPOR Evidence Alliance](https://sporevidencealliance.ca/) is a pan-Canadian research initiative designed to promote evidence-informed health policy and practice changes, and is made up of a network of researchers, trainees, patient partners, healthcare providers and health system decision-makers. Patients and the public are included throughout the Evidence Alliance’s [governance structure](https://sporevidencealliance.ca/about/governance-structure/), and [biographies](https://sporevidencealliance.ca/about/our-people/) of all members, as well as [Terms of Reference](https://sporevidencealliance.ca/wp-content/uploads/2021/04/SPOREA_Governance-Structure-and-Terms-of-Reference_UPDATED.pdf) for each committee can be found on their website. Detailed patient engagement activities are outlined in the [publication](https://www.facetsjournal.com/doi/full/10.1139/facets-2021-0133) *Patient engagement in the SPOR Evidence Alliance: Reflection and learnings*.

# International practices and examples with brief descriptions

## NIHR Applied Research Collaboration (NIHR ARC)

In collaboration with NHSX and the National Data Guardian for Health and Social Care, NIHR ARC commissioned a set of three online citizens’ juries about health data sharing in a pandemic between March and May 2021. As data governance policies have changed due to the Covid-19 pandemic, but with little public input, the goal of the citizens’ juries was to be able to consult with the general public about policy questions related to health data sharing during the pandemic. The [executive summary](https://www.arc-gm.nihr.ac.uk/media/Resources/ARC/Digital%20Health/Citizen%20Juries/Broken%20Files/12621_NIHR_Juries_Report_Exec_Summary_ELECTRONIC.pdf) and [full report](https://www.arc-gm.nihr.ac.uk/media/Resources/ARC/Digital%20Health/Citizen%20Juries/New%2012621_NIHR_Juries_Report_WEB.pdf) outline the project’s full scope of work, including methodologies and outputs. Files on [jury design documentation, materials and outputs](https://www.arc-gm.nihr.ac.uk/projects/Citizens-Juries-on-Health-Data-Sharing-in-a-Pandemic) are available for download at the bottom of the webpage.

## Understanding Patient Data (UK)

[Understanding Patient Data](https://understandingpatientdata.org.uk/) aims to make the way patient data is used more visible, understandable and trustworthy for patients, the public and health professionals. They work with patient groups, the health care sector, policymakers and other stakeholders to bring transparency, accountability and public involvement to the way patient data is used. Some key resources include a [quick-guide](https://understandingpatientdata.org.uk/sites/default/files/2021-10/Resource%20quick%20guide%20v%202.0.pdf) to provide stakeholders with material to help explain the use of health data, as well as [best practices in patient and public engagement](https://understandingpatientdata.org.uk/public-and-patient-engagement-activities) with examples of how to meaningfully engage the public in issues around patient data.

## Health Data Research UK (HDR UK) Public Advisory Board

The HDR UK Public Advisory Board sits within the HDR UK governance structure and provides strategic advice to the organization on its direction of work, including its [Public and Patient Involvement and Engagement](https://www.hdruk.ac.uk/about-us/patient-and-public-involvement-and-engagement/) (PPIE) strategy. Members work with HDR UK to encourage and enable effective health data science by involving patients and the public, advising on ways to demonstrate trustworthiness and build public confidence in their work, and grow public understanding of the safe and secure access to the use of health data for research. [Member biographies](https://www.hdruk.ac.uk/about-us/who-we-are/our-advisory-groups/) can be found on HDR UK’s website, and the board’s [Terms of Reference](https://www.hdruk.ac.uk/wp-content/uploads/2022/02/Jan-2022-Public-Advisory-Board-Terms-of-Reference.pdf) outline additional details on key activities and general membership.

## Sortition Foundation (UK)

The [Sortition Foundation](https://www.sortitionfoundation.org/) is a non-for-profit company dedicated to promoting fair, transparent, inclusive and effective deliberative assemblies. They offer bespoke selection and stratification services for deliberation events, and recently assisted in the creation of the [Citizens’ Jury on qCovid](https://www.sortitionfoundation.org/qcovid_2022_report?fbclid=IwAR3ZKFrZa8YQPAowzLNKb2bPAatukW3ACelbRavJVFK1aSTZZ72RxXGtDQg) to deliberate on the risks and benefits of using public health data to predict people’s risk of dying from Covid.

## Participedia

[Participedia](https://participedia.net/) is a global network and crowdsourcing platform for researchers, educators, practitioners, policymakers and activists interested in public participation and democratic innovations. They offer a searchable and editable database of content related to global public participation cases and methods. Select public engagement activities related to the use of health data include the [Health Research Authority Policy Framework Dialogue](https://participedia.net/case/5676), and the [Public Dialogue on Data Openness, Data Re-use, and Data Management](https://participedia.net/case/5694).

## The Data Assembly (The GovLab)

The [Data Assembly](https://thedataassembly.org/) is an initiative from [The GovLab](https://thegovlab.org/) to solicit diverse, actionable public input on data re-use for crisis response in the United States, initially focusing on the response to the Covid-19 pandemic. Deliberations with three “mini-publics” featuring data holders and policymakers, representatives of civic rights and advocacy organizations, and the public were conducted. Methodology and lessons learned are outlined in the [Data Assembly’s Responsible Data Re-Use Framework](https://thedataassembly.org/files/nyc-data-assembly-report.pdf).

## Involve UK

[Involve](https://www.involve.org.uk/) is the UK’s leading public participatory charity, working with governments, academics and the public to create and deliver new forms of public participation that will improve decision-making. Their website includes a variety of resources for public engagement, including descriptions of [public engagement methods](https://www.involve.org.uk/resources/methods) and where they fit on the spectrum of engagement. They highlight a number of projects and case studies on the importance of public engagement in health data issues. For example, in [the project How can People Make Informed Decisions about the Use of their Health Data?](https://www.involve.org.uk/our-work/our-projects/practice/how-can-people-make-informed-decisions-about-use-their-health-data)*,* Involve ran a series of deliberative workshops involving patient representatives to test a number of low-tech prototypes aimed at exploring a number of different areas such as language used, best visual representation, where and when the request for consent should be made, etc.

## Patient-centred Outcomes Research Institute (PCORI)

[PCORI](https://www.pcori.org/) works with healthcare stakeholders to identify critical research questions and answer them through comparative clinical effectiveness research, focusing on outcomes that are important to patients. All PCORI advisory panels include patient representatives, as well as other key knowledge users including practicing and research clinicians, health system decision makers, etc. Member biographies and additional details of each advisory committee can be found on their [website](https://www.pcori.org/about/pcori-advisory-panels). PCORI’s projects related to health data include [Educate to Engage Patients: Health Data](https://www.pcori.org/research-results/2017/educate-engage-patients-health-data), [Using Patient Generated Health Data to Transform Healthcare](https://www.pcori.org/research-results/2017/using-patient-generated-health-data-transform-healthcare), and [Open Data Roundtable Series: Sharing and Utilizing Data to Enhance and Protect Health and Well-Being](https://www.pcori.org/research-results/2018/open-data-roundtable-series-sharing-and-utilizing-data-enhance-and-protect-health-and-well-being)