

**Giving voice to the People: Use of citizen juries in shaping  
governance of digital health data in Canada**

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**Abstract:**

There has been a push towards digitalization of the Canadian health system to improve service accessibility, quality, and efficiency. Advocates for a digital health information network (HIN) believe that it will help shift the emerging health system be more patient-centred. Trust is paramount when establishing a functional HIN, but average Canadians are excluded from the on-going discussions. Citizen juries provide a transparent participatory process in which ordinary citizens are given an explicit opportunity to voice their opinions and be informed of the current issues. This policy brief recommends the use of citizen juries in shaping governance of digital health data.

**(100 words)**

**Keywords:**

*Public engagement, citizen juries, eHealth, electronic medical records, digital health data governance*

**Introduction:**

Digital information technologies have permeated our everyday tasks and interactions. With the internet, people can easily acquire goods and services using computers and smartphones. Every aspect of society is going through digitalization, and the government sector is no exception. It has been widely recognized that digitalization of public services such as taxes, immigration, and health care, will lead to significant cost savings, better integration within departments, and greater user satisfaction through improved quality of services.

There has been a strong push to digitalize the Canadian health care system in past decades as a way to improve service accessibility, quality, and efficiency. This transition process, however, has been long and perplexing to the average citizen. Many Canadians welcome the change, but they are also concerned about data privacy and security and feel that they are left out of the decision making process.

Public engagement is imperative in shaping governance of digital health data, because health matters affect individuals at a deeply personal level. This policy brief proposes the use of citizen juries to engage the general public on issues relating to use of their digital health data.

**Background:**

The Canadian health care system is publicly funded. All residents have access to certain hospital and physician services without paying out-of-pocket. Provincial and territorial governments are responsible for administering and delivering health services and insurance plans within their own jurisdiction, while the federal government sets up national guidelines and provides funding support.

Discussion of “the application of information and communications technologies in the health sector (1)” in Canada (eHealth) began in the early 1970s. Specific funding has been allocated in investing in eHealth since the 1997 Federal Budget (1). In 2001, Canada Health Infoway (CHI) was established to accelerate the adoption of digital health solution across Canada. It is an independent, non-for-profit organization funded by the federal government. The development and adoption of the Electronic Medical Record (EMR) is considered to be one

of the top priorities of CHI. EMR allows the sharing of health information amongst health care providers of different disciplines and the patients, and could also be used in research, education and public health initiatives.

The use of EMR varies across Canada. According to the Canadian Medical Association Workforce Survey in 2017, 85% of primary care providers use EMRs (2). Regional disparities exist due to the diverse systems, funding support, and priorities of the provinces and territories (3). It is noted that some EMR adopters only use certain features of the system while keeping other information in paper records (3, 4). Meanwhile, most Canadians remain outside the EMR system. According to a national survey commissioned by CHI, only 6% of respondents could access their EMRs in 2014. The figure has now risen to 22% in 2018. It is also noted that 73% of the respondents who cannot access their EMRs have expressed their desire to gain access (5).

Digital health information is subject to a specific set of privacy and eHealth laws depending on where the service was delivered and information collected, as health care is managed by the provincial and territorial governments. With recent technological advances, additional health data are being collected by other providers and/or the individuals themselves. There is a tremendous opportunity to create a digital health information network (HIN) that will provide a comprehensive view of an individual's health and will greatly promote shared decision-making between the patients and the service providers. By the same token, the data explosion creates a significant challenge in creating a functional, interoperable, but secure, HIN. Many Canadians have expressed their desire to be in a better position for managing their own health (5), but they are having difficulties in pinpointing how their digital health data are being stored and used. Citizens' opinions should be taken into account when establishing a HIN that they will trust and participate in.

CHI gauges the general public's opinions towards digital health through its regular surveys. "Better Health Together" campaign is developed to "raise awareness of the value and benefits of digital health among Canadians" through storytelling in the social media channels (6). In May 2017, CHI coordinated a "Better Health Together" workshop to engage citizens across the country in reviewing their Consumer Health Strategy (7). Public engagement initiatives on

digital health data issues are sporadic at best. Discussions on the governance of digital health data are done primarily amongst expert groups, healthcare professionals, and health authorities.

### **The “citizen juries” approach:**

First developed in the 1970s, citizen juries are a type of deliberative inclusive approach that seeks to engage ordinary citizens on a range of policy issues (8). A citizen jury typically consists of 12 – 20 diverse citizens that could best represent the overall demographic. These jurors are briefed in detail on the background and current situation relating to a particular issue, and presented with available alternatives. They are then asked to come up with conclusions that are most appropriate for their community after a period of group exercises and deliberations. The citizen jury will present their decision as they would in legal juries, often in the form of a report. The report could include recommendations for future actions or directions for the commissioning agency.

Citizen juries are a useful approach to involve ordinary citizens in the policy decision making process and intended to complement other means of consultation. They can be used to draw citizens into a participatory process where they generally feel “distanced from the decision-making process or a process that is not seen as being democratic” (9). Citizen juries are small enough to permit effective deliberations and are relatively inexpensive to run (10). They can also help gauge public opinions and reactions, and allow citizens to develop a deeper understanding of the policy issue at hand (9). Participants of the citizen juries will often share their knowledge and experience with others, thereby further improving a deeper and wider awareness of the policy issue within the community.

### **Applications of citizen juries:**

Citizen juries have been used in health policy decision-making in many countries, including Canada, UK, Australia, and the USA (10). The Scottish Health Council commissioned an extensive literature review on the citizen juries approach in 2017. The authors of the report acknowledged that there is a need to shift the culture of public services “from ‘doing to’ towards ‘doing with’ citizens”. Deliberative approaches such as citizen juries could provide a venue

where the general public could work together with the government agencies in designing what and how the public services should be provided (11).

Citizen juries are used to engage citizens of the Northern UK in exploring issues associated with the use and sharing of digital health data, as part of the Connected Health Cities initiative (12). Information regarding the jury selection and full jury reports are available online.

### **Conclusion & Recommendations:**

Canada is still at the early stage of the HIN development despite years of considerable effort. The complexity of a modern health care network and variations across regional health systems create a significant obstacle in developing and implementing an interoperable HIN.

There is a much stronger emphasis placed on the patient in the emerging health care system. However the provider-centric culture persists within the existing system and is reflected in the information asymmetry between the healthcare provider and the recipient. Future directions on the governance of digital health data still derive mainly from the “insiders”. It is interesting to note that the “citizen” participants in the 2017 CHI workshop all have previous exposure to CHI or other pertinent public decision-making forums.

Better understanding of patient preferences towards the access and sharing of their digital health data is critical in developing a system that they will trust and use, and more importantly, in building a better patient-provider relationship. It is important to keep in mind that everyone will at some point become a patient that requires healthcare. Just like everyone has access to reasonable health services, everyone should have the opportunity to be informed and participate in the discussions.

Given the current status, it is understandable that agencies should first focus on connecting Canadians to their EMR. Now is also an excellent occasion to invite their participation in shaping the governance of digital health data, which will become a fundamental block of the future patient-provider partnership. Digital health information is expected to be used in ways that go beyond traditional or well-known uses, so clear communication and

transparency during the development process will help gain people's trust and support. Citizen juries provide ordinary citizens an explicit opportunity to voice their opinions and to be much better informed of the current issues. The citizen juries also generate diverse, non-aligned viewpoints for the policymakers through a process that can be seen as fair, independent, and transparent.

CHI, in partnership with the provincial and regional health authorities, could set up several citizen juries across Canada to review the same use case scenario. This will allow sharing of 'best practices' that could potentially be adopted by all the participating agencies across Canada.

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