



HAL
open science

Patients' and Members of the Public's Wishes Regarding Transparency in the Context of Secondary Use of Health Data: Scoping Review

Annabelle Cumyn, Jean-Frédéric Ménard, Adrien Barton, Roxanne Dault,
Frédérique Lévesque, Jean-François Ethier

► To cite this version:

Annabelle Cumyn, Jean-Frédéric Ménard, Adrien Barton, Roxanne Dault, Frédérique Lévesque, et al.. Patients' and Members of the Public's Wishes Regarding Transparency in the Context of Secondary Use of Health Data: Scoping Review. *Journal of Medical Internet Research*, 2023, 25, pp.e45002. 10.2196/45002 . hal-04301491

HAL Id: hal-04301491

<https://hal.science/hal-04301491>

Submitted on 23 Nov 2023

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Review

Patients' and Members of the Public's Wishes Regarding Transparency in the Context of Secondary Use of Health Data: Scoping Review

Annabelle Cumyn^{1,2}, MDCM, MHPE; Jean-Frédéric Ménard^{2,3}, BCL, LLB, PhD; Adrien Barton^{2,4}, PhD; Roxanne Dault², MSc; Frédérique Lévesque², MSc; Jean-François Ethier^{1,2}, MDCM, PhD

¹Département de médecine, Faculté de médecine et des sciences de la santé, Université de Sherbrooke, Sherbrooke, QC, Canada

²Groupe de recherche interdisciplinaire en informatique de la santé, Faculté des sciences/Faculté de médecine et des sciences de la santé, Université de Sherbrooke, Sherbrooke, QC, Canada

³Faculté de droit, Université de Sherbrooke, Sherbrooke, QC, Canada

⁴Institut de recherche en informatique de Toulouse, Toulouse, France

Corresponding Author:

Jean-François Ethier, MDCM, PhD

Groupe de recherche interdisciplinaire en informatique de la santé

Faculté des sciences/Faculté de médecine et des sciences de la santé

Université de Sherbrooke

2500 boul. Université

Sherbrooke, QC, J1K 2R1

Canada

Phone: 1 819 346 1110 ext 74977

Email: jean-francois.ethier@usherbrooke.ca

Abstract

Background: Secondary use of health data has reached unequalled potential to improve health systems governance, knowledge, and clinical care. Transparency regarding this secondary use is frequently cited as necessary to address deficits in trust and conditional support and to increase patient awareness.

Objective: We aimed to review the current published literature to identify different stakeholders' perspectives and recommendations on what information patients and members of the public want to learn about the secondary use of health data for research purposes and how and in which situations.

Methods: Using PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines, we conducted a scoping review using Medline, CINAHL, PsycINFO, Scopus, Cochrane Library, and PubMed databases to locate a broad range of studies published in English or French until November 2022. We included articles reporting a stakeholder's perspective or recommendations of what information patients and members of the public want to learn about the secondary use of health data for research purposes and how or in which situations. Data were collected and analyzed with an iterative thematic approach using NVivo.

Results: Overall, 178 articles were included in this scoping review. The type of information can be divided into generic and specific content. Generic content includes information on governance and regulatory frameworks, technical aspects, and scientific aims. Specific content includes updates on the use of one's data, return of results from individual tests, information on global results, information on data sharing, and how to access one's data. Recommendations on how to communicate the information focused on frequency, use of various supports, formats, and wording. Methods for communication generally favored broad approaches such as nationwide publicity campaigns, mainstream and social media for generic content, and mixed approaches for specific content including websites, patient portals, and face-to-face encounters. Content should be tailored to the individual as much as possible with regard to length, avoidance of technical terms, cultural competence, and level of detail. Finally, the review outlined 4 major situations where communication was deemed necessary: before a new use of data, when new test results became available, when global research results were released, and in the advent of a breach in confidentiality.

Conclusions: This review highlights how different types of information and approaches to communication efforts may serve as the basis for achieving greater transparency. Governing bodies could use the results: to elaborate or evaluate strategies to

educate on the potential benefits; to provide some knowledge and control over data use as a form of reciprocity; and as a condition to engage citizens and build and maintain trust. Future work is needed to assess which strategies achieve the greatest outreach while striking a balance between meeting information needs and use of resources.

(*J Med Internet Res* 2023;25:e45002) doi: [10.2196/45002](https://doi.org/10.2196/45002)

KEYWORDS

transparency; information; means of communication; public; patients; secondary use; health data; learning health systems

Introduction

Potential Benefits From the Secondary Use of Health Data

In recent decades, the potential benefits of secondary use of health data have been highlighted in many different contexts, including health systems governance, quality improvement [1], point-of-care decision-making [2-4], and research [5]. While a unique, unanimously accepted definition of secondary use remains elusive, we will operate under the premise that it covers any use beyond the initial intent of data collection. Given the resources required to generate health data, using them to their fullest extent to improve health is a laudable goal. Nevertheless, health data often describe an individual, and thus their autonomy regarding the use of data also needs to be considered [6]. For individuals to be able to weigh in on the use of data about them, they at least need to be aware that data generated for a primary reason (eg, during a consultation with a physician) have values above and beyond the specific context for which they were created and can therefore be used for secondary goals such as research projects or systems policy research. As mentioned previously, the secondary use of health data covers a broad landscape, and the scale of expected benefits (eg, How much? How soon? Who?) varies from one use to the other, which could modulate how individuals react to different types of secondary use.

Therefore, while the potential of secondary use of health data for research purposes is seen as promising to many stakeholders in the academic and health care worlds, trust regarding data sharing in novel contexts should not be considered as a given [7]. Indeed, despite substantial evidence that most individuals support the secondary use of health data, this support is neither unanimous nor unconditional [6,8-11]. Stakeholders including patients and members of the public express different needs that touch upon trust and agency [12]. Controversial initiatives such as care data in England [13], the National Electronic Health Record System in Australia [14], and other incidents involving unconsented and unauthorized use of data [15-17] have contributed to some mistrust in the population, which may then tend to develop greater sensitivity to the risks associated with data sharing and health data in general [7,12]. In addition, few people seem to be aware that the secondary use of their health data is already permissible in certain circumstances [18]. In all these situations, some stakeholders perceived a lack of transparency. Although transparency is unquestionably identified as an essential element of social license regarding the secondary use of health data, it is not always clearly defined. For example, Kisekka et al [19] showed that information accuracy and availability are important parameters for the adoption of

e-portals; however, an open question is which kind of information is expected by the stakeholders and under which modalities of communication. Furthermore, technological advances offer new ways for transparency to become tangible and bring forth strategies for more open communication [20]. Therefore, there is a real need to better understand the actual expectations regarding transparency with regard to secondary use of health data.

Potential of Learning Health Systems

The fact that a research project is targeting a common health issue such as heart attacks does not guarantee a rapid and substantial benefit as an important justification for valuing the secondary use of health data. For example, in 1982, studies identified a class of medication, namely β -blockers, as useful in reducing mortality in the context of heart attacks. Nevertheless, it took more than 20 years to confirm the widespread adoption of this simple and relatively inexpensive intervention [21].

To increase the pertinence of projects undertaken, the rapidity at which the resulting new knowledge is put into action, and therefore the benefits to patients, learning health systems (LHSs) have been proposed. They are a model that embodies how linking data from clinical care and research can create new knowledge and improve clinical decision-making [22]. Recent publications have reported the success of early LHSs [1,23,24], which is encouraging. Moreover, this integration of care delivery, research, and effective knowledge transfer can be implemented as described in the study by Faden et al in 2013 [25], in which a new ethical contract is based on a large engagement of all stakeholders (including patients), transparency (both on ongoing activities and data supporting them), and accountability to demonstrate benefits for the participants. While communicating about secondary data use is important, it is particularly essential in an LHS context.

Aims

This scoping review aims to describe how transparency is portrayed by various stakeholders regarding the secondary use of health data in a research context. Specifically, we wanted to address the following questions: (1) What information do patients and members of the public want to learn about the secondary use of their health data for research purposes (what)? (2) How do patients and members of the public want to interact with this information (how)? and (3) In which situations (when)? The objectives of the scoping review were elaborated by a team composed of an expert in health informatics (J-FE), an expert in research ethics (AC), a legal expert (J-FM), and an expert in ethics and philosophy of science (AB).

The study aims to capture a broad landscape of the literature to serve as a cornerstone of the upcoming consultations with patients and members of the public to identify the operational requirements of a transparency portal as LHSs are deployed in the province of Quebec. Therefore, resources specifically targeting an LHS context were identified when available, but the search was not restricted to only these as the LHS field is relatively young.

Methods

Overview

We addressed our research objectives by performing a scoping review following the 6-stage methodology framework by Levac et al [26] (based on the framework initially proposed by Arksey and O'Malley [27]), which we reported in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) framework [28] (the PRISMA-ScR checklist is available in [Multimedia Appendix 1](#)). Our aim was to obtain a large spectrum of articles, from original research to opinion papers, law articles, and workshop reports. Our review protocol was finalized in July 2021, but was not made publicly available.

Definition of Health Data in This Review

We defined health data as data generated either in the context of health care, whether found in patient charts or connected objects, or in the context of health care research to capture perceptions about all kinds of secondary uses. In these secondary uses, we included approved future uses of biobank data because the literature on that matter was quite relevant to our research question.

The Concept of Transparency in This Review

The term “transparency” characterizes a process of information communication that follows certain norms about the amount, type, and framing of information that is shared. For example,

the process of informing a person about access to one's health data by third parties through a poster in a health professional's office might be characterized as aiming at being transparent. By extension, the term “principle of transparency” can refer to a normative principle that instructs to communicate information in a transparent way (in the first sense). Thus, the 2 senses of the term “transparency” are closely linked. Since the 2 core notions of transparency are its relevance and its easiness to understand, this suggests that an investigation of transparency should concentrate on questions such as “What information should be conveyed?” “How should it be conveyed?” “In which circumstances should it be conveyed?”

Search Strategy

An extensive literature search was performed for articles up to November 2022 in the following bibliographic databases: Medline, CINAHL, PsycINFO, Scopus, Cochrane Library, and PubMed. The search strategy was developed with the assistance of a university librarian and was adapted to each database (the detailed search strategies are provided in [Multimedia Appendix 2](#)). The 5 core concepts used in the search strategy were patient, public, citizen (and synonyms); health data, medical data, data use, data sharing (and synonyms); attitude, view, perspective, opinion, position (and synonyms); information, transparency, communication, dissemination, awareness, notification, education (and synonyms); and research, secondary use, LHS (and synonyms). We did not have to limit the time span.

Eligibility Criteria and Screening

Two reviewers (RD and FL) independently screened the titles and abstracts of all articles identified by the search strategy (after removing duplicates), followed by a full-text review of the remaining articles. To perform an in-depth and broad research, no article was excluded based on year, type, or location of publication. The eligibility criteria are presented in [Textbox 1](#).

Textbox 1. Eligibility criteria.

Inclusion criteria

- Language and article availability
 - French
 - English
 - Full-text availability
- Article type
 - Original articles
 - Commentary or opinion papers
 - Policy or law articles
 - Ethics articles
- Population
 - Reporting at least patients, members of the public or other experts' (eg, health care professionals and researchers in various domains) point of views or recommendations
- Outcomes
 - Reporting at least 1 of the following elements: What information to communicate to patients or members of the public; how to communicate the information (eg, format and support).
- Context
 - Secondary use of data
 - Uses in research
- Data type
 - Health data such as hospital data, electronic record data, administrative data, or medical data

Exclusion criteria

- Language and article availability
 - Other language
 - Abstract only
- Article type
 - Review articles (Review articles that met the other inclusion criteria were screened to include potential studies of interest.)
 - Study protocols
- Context
 - Primary use of data (eg, for health follow-up)
 - Other secondary uses of data (eg, quality improvement, safety monitoring, clinical decision-making, or policy making)

The 2 reviewers first performed a joint screening on a 10% sample of the articles to familiarize themselves with the selection criteria and to standardize their approach. Every discrepancy between the 2 reviewers was discussed to obtain a consensus. If a consensus could not be reached, a third reviewer (AC or J-FM) was consulted. The team met weekly to discuss the progress of the literature review. The search and screening process was initially completed in July 2021 but was updated up to November 2022 following the same methodology to capture and include recent publications.

Data Extraction and Analysis

The extraction, organization, and analysis of information from the articles included in this scoping review was performed using NVivo 11 Pro software (QSR International), a tool to conduct extensive literature reviews [29]. On the basis of the aforementioned research questions and objectives, the research team developed a codebook with an initial tree of nodes to chart the data into NVivo. This codebook also includes the coding procedure and definitions of the nodes for the reviewers responsible for the data extraction. All selected articles were

imported into NVivo software. Four reviewers (RD, FL, AC, and 1 research assistant) coded all the articles, a process that was subsequently validated by 2 reviewers (AC and J-FM). All reviewers received detailed training in the software, project, and codebook. They all simultaneously coded a sample of the articles to familiarize themselves with the tree of nodes and coding method. During training, the reviewers' coding was compared with determine whether their approach to data extraction was consistent, and discrepancies were discussed in team meetings. This process was repeated until all reviewers were comfortable with the coding. The coding was performed in an iterative manner to allow the emergence of new concepts and themes in the tree of nodes. Weekly team meetings were held between reviewers to discuss and validate coding decisions as well as emerging themes. The information was subsequently analyzed to examine what information, time frame, and means of communication were proposed, recommended, or desired for various research activities regarding the access and secondary use of health data for research purposes. We also aimed to identify topics that were not addressed in the literature for future work. The following 3 themes emerged from a text analysis: content to communicate, how to communicate, and situations

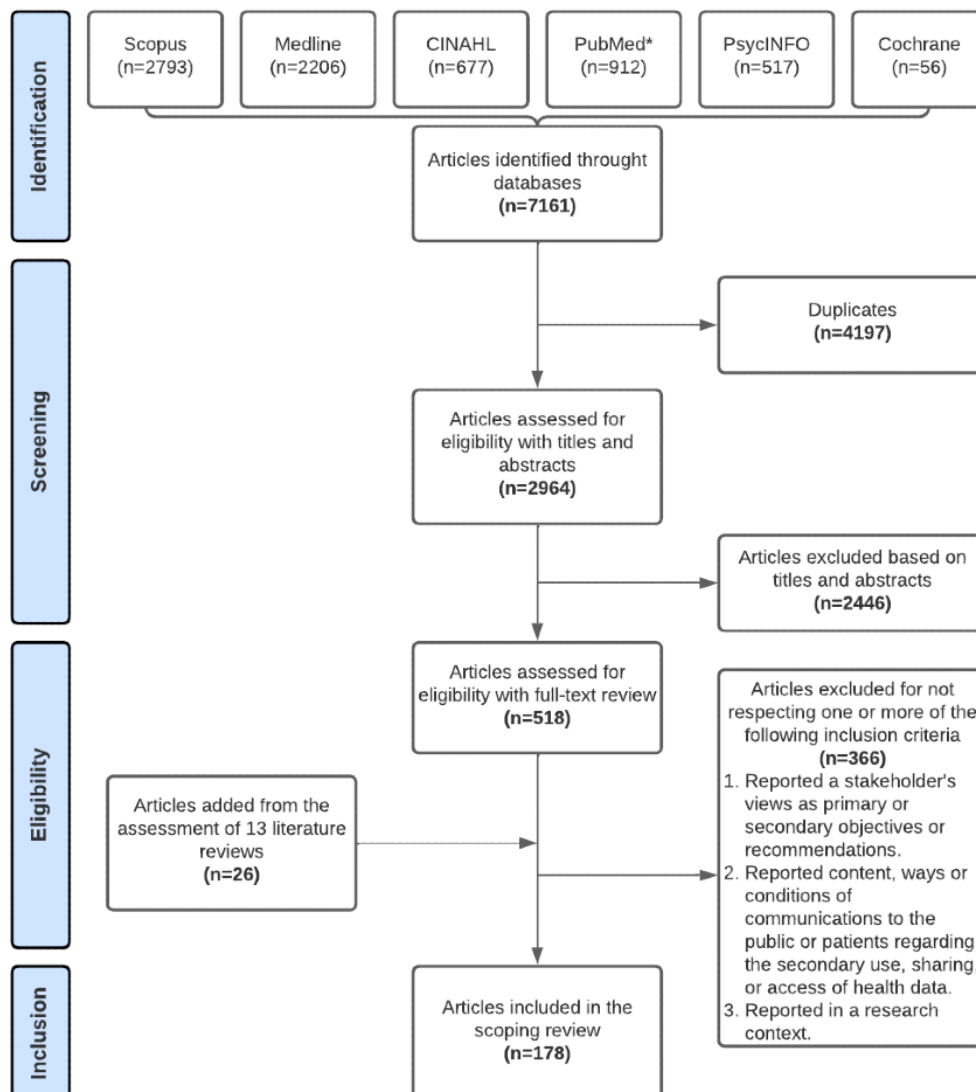
in which communication becomes relevant. A fourth theme also emerged, namely, the impacts of communication, which were further divided into potentially negative, neutral, or positive impacts. This last theme was not directly linked to our research question and was the focus of a separate article. Note that the literature update from July 2021 to November 2022 did not bring any new concepts to light but rather confirmed that we had reached theoretical data saturation.

Results

Search Outcome and Bibliographic Overview

The detailed selection process is illustrated in Figure 1. After removing duplicates, 2964 articles were identified through the database search. The screening of titles and abstracts led to the assessment of 518 articles in a full-text review. In total, 152 original articles and 13 review articles met our inclusion criteria. The manual assessment of the references from the review articles added 26 original articles. Only original articles of those reviews that met our inclusion criteria were included in the final selection of this scoping review. Finally, 178 articles were included in this scoping review.

Figure 1. Article selection process. *Restricted to publications in the last 2 years for more recent indexation.



The main characteristics of the articles included in this review are presented in [Table 1](#), and 178 complete references are presented in [Multimedia Appendix 3](#) [6,8,11,18,19,30-202].

Table 1. Characteristics of articles included in the scoping review (n=178).

Characteristics	Articles, n (%)
Year of publication	
2002-2006	9 (5.1)
2007-2017	71 (39.9)
2018	10 (5.6)
2019	27 (15.2)
2020	22 (12.4)
2021	24 (13.5)
2022	15 (8.4)
Continent where study was conducted^a	
North America	86 (48.3)
Europe	69 (38.8)
Asia	6 (3.4)
Oceania	5 (2.8)
Africa	4 (2.2)
Worldwide	8 (4.5)
Study design^b	
Qualitative	91 (51.1)
Quantitative	52 (29.2)
Mixed approach	9 (5.1)
Commentary	9 (5.1)
Law and politics	16 (8.9)
Descriptive	1 (0.6)
Perspectives reported in the study^c	
Public	68 (38.2)
Patients	59 (33.1)
Researchers	26 (14.6)
Law and politics	22 (12.4)
Ethics	15 (8.4)
Health care	11 (6.2)
eHealth or informatics	8 (4.5)

^aNorth America: Canada, United States; Europe: United Kingdom, Iceland, Ireland, Sweden, Italy, Germany, Denmark, Switzerland, Norway, Portugal, the Netherlands, Belgium, France, and Finland. Asia: Saudi Arabia, Taiwan, China, India, and Japan. Oceania: New Zealand and Australia. Africa: Ghana, Uganda, Zambia, Kenya, and Singapore. Worldwide: studies with multiple countries involved.

^bQualitative: workshops, interviews, focus groups, councils, and panels; Quantitative: survey and Delphi; Mixed approach: combination of quantitative and qualitative designs; Commentary; Law and politics: ethical, legal, or governance frameworks, guidelines, requirements, and other policies; and descriptive study.

^cNot mutually exclusive. Public: Indigenous communities, minority community members, older adults, blind and low-vision communities, and early adopters of emerging technologies. Patients: susceptible, rare diseases, cancer, cardiac, Parkinson disease, mental health, pediatric (parents and families), and representatives of patients' organizations. Researchers: research participants, students, researchers, recruiters, sponsors, investigators, scientific staff, data infrastructure employers and managers, and research governance experts. Law and politics: policy makers, legal professionals, and regulatory staff. Ethics: ethicists and research ethics committee members. Health care: health care professionals, health managers, and health systems leaders. eHealth or informatics: eHealth experts, device or app developers, and data-sharing experts.

What to Communicate?

There were 2 distinct types of content that emerged from this review. We refer to them as “generic content” (communication on broader aspects than the secondary use of their own personal health data) and “specific content” (communication on the secondary use of their own personal health data).

Generic Content

Overview

[Table 2](#) lists an overview of the types of generic content that various stakeholders wish to see communicated with exemplary citations extracted from the studies reviewed.

Table 2. Types of generic content: description and examples of stakeholders' perspectives.

Type of generic content	Description	Exemplary citations of different stakeholders extracted from reviewed studies
General information on secondary use of health data [11,19,30-61]	<ul style="list-style-type: none"> Education around data types and secondary uses [49,54-56,59-61] Education on Research Ethics Board role [11,46,50-53] 	<ul style="list-style-type: none"> "[...] I think that education in general is a really good tool for the layperson to understand what's happening and I just think that that's probably the key, educating away the fears but also disclosing—what are we responsible for? What could happen? It's going to help people trust what you're doing a little more too" (biobank participant [39]). "Participants clearly identified a number of areas where there was a need for more knowledge and work around data sharing. [...] There were four main areas where greater knowledge was required: (1) clarity regarding the legal and clinical implications of shared data for patients and providers, (2) an understanding of legislation across Canada, (3) decision-making about what data are needed and (4) being aware of the context of electronic medical records [EMR] data" (Terry et al [35] on the views of a variety of stakeholders).
Information on data governance [11,31,33,34,36,40-42,49,52-54,57,59,60,62-118]	<ul style="list-style-type: none"> Who: identity of data overseers [11,31,41,49,53,76,83,85,98,100-102,115] and data users [11,31,52,73-77,79-81,86,91,113,114,117,118] What and what for: type of data used and type of secondary use [53,54,59,60,62,75,86,94,108-110,117,118] With whom: data-sharing practices [59,60,65,90,97,105,106,111,118] How: sources of funding [95,96], safeguards [34,53,73,103,104,112] 	<ul style="list-style-type: none"> "Respondents identified biobank objectives, governance structure and accountability as the most important information to provide participants. Respondents' concerns about biobanking generally centered around the control and ownership of biological samples and data, especially with respect to potential misuse by insurers, the government and other third parties" (Joly et al [64] on the views of members of the public). "I'm just trying to say there is this framework, you know we say that there is a governance system in place which will protect the patient and we can look at them like we do the financial institutions and we're quite happy with how they exist, well they're quite well developed. There's a framework around this and we want some assurance" (patient with a rare disease [67]). "Well, I did not know how freely they could share the information, that they are actually sharing them with payers. So, something needs to be done with that because we have a right to know where our information is going [...]" (oncology patient [114]). "I guess, for me I think it's not so much the party accessing the data, but rather how is the data being used for and for what purpose. So knowing that, then I'm able to make a better decision as in whether I want to participate. ... if it's from a big pharmacy company, then I think it may be for a commercial gain, but again it still help people. So I guess it's still the purpose, how the data being used, the purpose what is it used for" (member of the public [94]). "Similar to other findings [...], our discussants emphasized, however, that disclosure of data-sharing practices was important in order to make a truly informed decision and fulfill the fundamental ethical principles of participant autonomy and respect" (Haga and O'Daniel [63] on the views of members of the public). "Overall, workshop participants felt that if they knew more about the processes and safeguards in place, they might feel more empowered, and hence more open and trusting in the decision-making process around data collection and sharing (and may not, therefore, need to opt-in)" (Ipsos [112] on the views of members of the public).
Information on ethical and legal aspects [31,33,35,39,40,52,53,60,63,64,71,73,75,77,80,81,85,86,103,111,118-131]	<ul style="list-style-type: none"> Legal framework [35,81,124,126,127] Confidentiality and privacy measures [33,60,63,71,75,80,86,117,118,123,129,130] Security breach [31,52,60,103] Penalties for misuse [31,39,60,73,77,85,103,111,124,128] Participant rights [73,120-122,131] Intellectual property rights [52] 	<ul style="list-style-type: none"> "It was also suggested that there would be some benefit in raising public awareness of the complex legal environment surrounding data sharing and that this might demonstrate the legitimacy of researchers' access to data" (Mamo et al [40] on the views of members of the public). "How it is being used, how I am protected from corrupt or evil activities, and what precautions are taken to protect it" (member of the public [64]). "To protect our privacy in a world where we no longer control our data, we must obfuscate health data, penalize the misuse of health data, and improve transparency around who shares our data and for what purposes" (expert opinion [111]).
Information on technical aspects [33,34,38,40,52,53,62,63,73,78-80,82,83,86,91-93,95-97,103,106,118,120,130,132,133]	<ul style="list-style-type: none"> Data linkage [53,83,96,103,132] Types of data sets [34,62] Whether medical records are accessed [78] How data are shared [38,80,91,92,106,130] Data security [52,73,79,97,103,117,120,133] Duration of data storage and how they are stored [78,93,95,97,118] 	<ul style="list-style-type: none"> "I would want to know what kind of security the central network is using. Are they using any type of encryption at all, who has access to the system? How do they maintain that type of access, you know, just general [questions]" (patient [40]). "Patients also brought up the importance of restricting data access, oversight of such restrictions and voiced specific questions about data security, for instance, wanting details on how the data would be transferred. Some patients expressed uncertainty about current practices; as one patient said, 'I don't know who has access to my information'" (Mazor et al [106] on the views of patients). "Kept in a very safe location. I hate qualifiers like that. It doesn't make me feel very safe. I: What would make you feel safe? P: When I see 'will be kept in a very safe location.' I would want specifics" (patient [73]).

Type of generic content	Description	Exemplary citations of different stakeholders extracted from reviewed studies
Information on scientific aspects [11,31,46,53,64,65,68,73,75-77,79,85,89,92,93,95-97,99,115,132,134-136]	<ul style="list-style-type: none"> Nature of the research and objectives [11,31,64,68,76,77,79,95,97,115,132,136] Research methodology [79,93] Risks and benefits [46,53,65,73,75,77,79,85,89,92,95,96,99,134] Data validity and possible biases [75,79,96] 	<ul style="list-style-type: none"> “Around half of the respondents want to receive an easily understandable summary of project (51%) and information about the management rules (49%)” (Courbier et al [76] on the views of patients with rare diseases). “It would be very helpful to the reader and potential study subject to have some, at least, some examples of the type of research the researchers intend to do” (patient [73]). “[My mobile data] shows a terrible step count, but that’s because I don’t hold my phone while playing netball, long walks etc” (member of the public [75]).

General Information on Secondary Use of Health Data

The need for general knowledge about information systems and data-driven research was a transversal theme in our review (Table 2, row 1), whether in the context of biobanking [19,30-45,71,83,84], precision medicine [92], mining of health data [34,44,49,72,115], or data sharing with the industry [71,73,75,134]. Some stated that the need for education extended to all stakeholders, including patients, research participants, and researchers. Clinicians were also targeted for education on how to integrate genomics into clinical care [40,55,137] and training in information technologies [120]. Members of the public and research participants highlighted the value of [31,83]

communicating positive messages about how data are used: ‘promoting the success stories’, And I can see an advantage in updates because I think it creates a positive view of things, a positive view while there’s so much bad information. You know that here’s a group of people working for the human good and you’ve participated in it, you know. It’s uplifting really [Biobank participant]

Information on Data Governance

The second set of generic content is related to data governance (Table 2, row 2). Comprehensive and transparent governance emerged as a key point in the literature from biobanking [64,69,78,102] and appeared to apply to more novel uses of data; for example, secondary use of anonymized mobile phone data [33,65,66,80], unregulated mobile apps [81], novel data linkages [75,132], sharing genomic data [57,85,91], distributed data networks [40,109,138], or artificial intelligence [79,108,139]. The most common content elements pertain to the structure of governance, nature of secondary use [42,76], and the identity of data users, in particular if sharing with the industry [38,40,61,75,93,97,104]. In a recent survey, knowing the names of the individuals in charge of data governance was particularly important if identifiable health data were being accessed in the context of data mining [115]. In the same line of thought, an analysis on 836 respondents by Kisekka et al [19] concluded that in the context of e-portals and health technology use, “[...] individuals worry more about who possesses the right to access their health data (i.e., who, what, when, and why) than the mechanisms used to safeguard data from unauthorized access.” Of interest, the composition of the governance body; distribution of power; presence of a data overseer (at times

referred to as an ombudsman); and the integration of patients, citizens, or the community in governance were suggested as important information to foster trust.

Information on Ethical and Legal Aspects

Stakeholders wished to obtain some information on the legal frameworks protecting the data, confidentiality and privacy measures, penalties for misuses, participant rights, and intellectual property rights (Table 2, row 3). The participant rights most mentioned were related to a need for control over future use, with a focus on individual consent. In a survey of public perspectives on genomic data sharing with responses from 36,268 individuals across 22 low-, middle-, and high-income countries, the right to withdraw one’s data was ranked highly as a measure to increase trust (second to information on who would benefit from the data sharing) [85].

Information on Technical Aspects

Many raised the issue of technical information, such as measures taken to protect the data (Table 2, row 4). Fewer stakeholders wished for information about data linkage, how data are shared, and information security.

Information on Scientific Aspects

Some members of the public and patients suggested that information regarding the nature of the research would be welcome with a focus on general objectives [64] and benefits for the self or society [33,37,85,99,134] (Table 2, row 5). Stakeholders occasionally raised the issue of communicating measures taken to ensure data accuracy or validity [75,79,96].

Specific Content

Overview

Table 3 presents the major types of specific content that emerged from our review. Of note, when the comments concerned specific content, they emphasized the motivation for receiving such content. This was different from the comments on generic content that focused more on details around the type of content; hence, the difference in headers for the second column of Tables 2 and 3.

By far, the most frequent elements cited in the literature for specific information were related to the return of results from individual tests (Table 3, row 2) and the sharing of one’s data (Table 3, row 4).

Table 3. Types of specific content: motivations and examples of stakeholders' perspectives.

Type of specific content	Motivation for receiving this content	Exemplary citations of different stakeholders extracted from reviewed studies
Information updates on the use of one's data [48,51,68,83,95,105,110,131,138,140-145]	<ul style="list-style-type: none"> To remain informed [68,110,131,138,142] To remain engaged [68,78,87,129,140,144] As a form of reciprocity [83,117,145] 	<ul style="list-style-type: none"> "I'd probably just want to be told that the study had expanded a little bit... that it was something different. Yeah, to keep everything above board. I would still say go ahead and use it, but... provided that the patient is aware" (patient [68]). "Concerning genetic data, all interviewees thought that next-of-kin should be informed about the fact that post-mortem genetic data analysis is taking place and be given the choice to be contacted about findings with potential relevance for their own health, if no prior preferences had been reported by the deceased" (Bak et al [54] on the views of patients and family members). "Well, it is all about giving and taking. You are giving information about yourself, about your state of health, in the end intimate details. And in return I want something back [...]" (member of the public [83]).
Information on results from individual tests [41,51,54,64,69,70,78,80,83,98,118,119,127,140,144,146-154]	<ul style="list-style-type: none"> For follow-up on one's health [51,54,70,98,127,144,146,147] As a form of reciprocity [41,78,83,118,146] As a condition for participation in research [80,83,148] To mitigate concerns about privacy [119] 	<ul style="list-style-type: none"> "I never heard any results. Our specimens [are] just being kept, being used however they might. What I would like to see is if specific tests are run. I would like to know the results" (research participant from an Indigenous community [144]). "I thought it would be great if I could delve into the relationship between my... genealogy and my cancer" (patient [146]). "To participate in a study where you get specific results would be very, for me, very positive. It would make me feel that I am contributing more instead of being lumped into this mass of people" (patient [146]).
Information on global research results of projects that used one's data [41,47,49,50,53,54,69,76,78,80,81,92,97,105,118,127,128,135,138,143,144,146,155-160]	<ul style="list-style-type: none"> For transparency and to increase trust [36,49,53,77,78,89,97,105,118,128,143,144] To help individuals or communities make informed choices about their health [47,50,78,92,127,129] As a gesture in return for participation [51,53,54,76,81,118,143,157] To share successes and increase research efficiency [41,77,83,105,138,143] If individual results are not available [146] 	<ul style="list-style-type: none"> "[...] I think if I was to take part in anything like this I'd like to be able to see how the research was actually being used and its effects within society and how it's helping people; that would be quite important for me to get something back" (biobank participant [83]). "When asked directly if they would like to be informed about the outcome of a data-sharing project in which they are participating, almost 100% of the respondents (99.7%) answer positively" (Coubrier et al [76] on the views of patients with a rare disease). "Yes, okay, you're going to share your data, but now we want you to share the results, positive or negative... One of the conditions for say getting our data is you have to share it and that shareable thing can be shareable with the public as well" (Parent of participant in a pediatric repository [138]). "It makes you feel like... what you've done is helpful and meaningful" (biobank participant [157]). "I'd like to know the results and whatever the issue is, how we can help communities, how we can help one another. Just what the next steps are. Where do we go from here?" (research participant from an Indigenous community [144]). "I mean, I would prefer linked because obviously there's personal interest there, but if it's done without that then I'd still be interested in the overall results" (patient with cancer [146]).
Information on the sharing of one's data [11,45,48,51,60,62,63,67,73-75,78,80,81,83,86,88,95,99,100,105,113,115,118,119,121,135,140,141,143,155,158,159,161-166]	<ul style="list-style-type: none"> To retain control over future use [45,67,73,75,81,83,88,99,100,113,118,119,121,143,155,159,165] To know who can access or has accessed the data [63,74,80,161] To enact ongoing consent [11,48,60,95,105,140,141,143] 	<ul style="list-style-type: none"> "I don't need to manage it but do want to know who and when they check my file. That way I can decide whether grant access or not" (patient [45]). "Knowing what they're doing or what they're planning to do. To know exactly what everything [is that] they're doing... and when and how it's been used. Because, like I said, because it's her genes, her stuff—you know" (parent [155]). "One participant said they would need to know, 'exactly who, where, [and] how my information will be used [...]' (Franklin et al [80] on the views of a patient with cancer). "I'd like to be notified anytime anybody accesses my medical records. Even if it's my primary care physician... I'd either be notified through email or whenever you log on... When you log on, you should be able to see a list of everybody who's accessed your file. If it's electronic, you'd be notified if they're trying to access something that's more confidential" (patient [74]). "I think however they plan to [share the data]—they should inform so that you know what they are doing, and [where] it's going to go—any method that they use" (member of the public [63]). "Yeah well, I feel if it's confidential it's confidential... and it's anonymous, so... I suppose maybe I'd prefer to know personally... but then if you never know it is going to be released then it's not going to bother you. But personally, I would prefer to know" (patient [161]). "I would like to be asked because if I think it's important and it can help some sick people to be healed, yes, there's no problem. But if I see that it's not relevant and that it could be a bit of anything, then I might refuse" (member of the public [11]).

Type of specific content	Motivation for receiving this content	Exemplary citations of different stakeholders extracted from reviewed studies
Information on how to access one's data [44,53,60,74,79,85,99,100,109,111,129,167,168]	<ul style="list-style-type: none"> To be able to analyze one's data [74,111,129,167] To be able to verify one's data [44,53,60,79,85,109] To be able to withdraw data [85,168] 	<ul style="list-style-type: none"> "If they collect the data, you should have some sort of report. You could say when something is missing" (member of the public [79]).

Information Updates on the Use of One's Data

Patients and members of the public proposed that information updates be sent at the time of secondary use of their data (Table 3, row 1). Some referred to a need for control over future use, whereas others saw the ongoing relationship as a path to engagement or as a form of reciprocity. Of note, the need for information and control appeared prominently in certain groups, including racial and ethnic minorities [18,38], people who have lived through experiences of exclusion [169], and members of Indigenous communities [78,92,144].

Information on Results From Individual Tests

Across the literature, patients and members of the public alike expressed a strong expectation for being informed of results from tests conducted in research contexts (Table 3, row 2), even when it only concerned a marker for disease susceptibility [56], an indication of increased or decreased risk [153], exploratory (for example microbiome) research [127], and even when not performed in a certified laboratory [148]. This expectation was often merged with the request of the right to access one's clinical data, which is outside the scope of the secondary use of health data for research. Clinicians and researchers, perhaps more cognizant of the distinctions between results that are part of a diagnostic process and nonvalidated research results, were less unanimously in support of the return of results [127,156,170].

In a cross-sectional study of the general Dutch population, participants wanted to receive both individual and aggregated results, with a preference for the former [69]. Notwithstanding this important preference for the return of individual results, many underlined the associated challenges, including the interpretation of results by the individual participants [127,146,152], and to a lesser extent, the risk of breach of confidentiality [150]. In addition, other factors seemed to influence preferences regarding the return of individual results, such as whether the medical condition was rare [76]; whether a health professional would be available to explain the results [69]; whether it had been agreed upon at the time of initial consent [81,91,163] (eg, at time of broad consent in the context of a biobank); whether there would be sharing of data with third parties [97], in particular those belonging to nonregulated, nonresearch settings [81]; and whether there might be logistical hurdles or excessive use of resources [146,152,170]. Indeed, many biobank participants may be primarily driven by altruistic motives and do not wish to allocate excessive resources to the return of results [83]. A participant in the study by Richards et al [157] stated the following:

Because the most important thing is to find, um, is the research itself. That's the most important thing. So, to me, getting updates on what's going on is a nice to have, but it's not a must have. [Biobank participant]

On the other hand, the return of results seemed to mitigate privacy concerns for other biobank participants [119].

Information on Global Research Results

The return of global research results of projects that used one's health data (Table 3, row 3) was another important theme for several stakeholders, including members of Indigenous communities. Return of global results, whether positive or negative [138], feeds interest, fosters trust, and can permit individuals and communities to take more informed decisions. Participants from Indigenous communities underlined how providing information would be the way to gain and maintain their communities' trust in research [78,89,144]. It was also seen as a gesture of gratitude in return for participation. Interestingly, in a survey of 80 Dutch researchers involved in biobank research, 23% disagreed in part or completely with the statement: "Participants have to be informed about aggregate research results" [156].

This opinion was echoed by 81.6% of patients with cardiovascular disease who responded to a survey distributed by the European Heart Network [135].

Information on How to Access One's Data

Information on how to access one's data (Table 3, row 5) was not frequently mentioned in the context of governance but seemed to be increasingly mentioned in recent years by members of the public in relation to a need to take control of one's health, ensure data accuracy, and exert some control in the context of novel health data uses [44,79,85] or sharing of genomic data [155]. In the context of data mining, Watson and Payne [44] stated the following:

Structures to allow individual access are required to address inaccuracies in the data and to provide a sense of fairness and comfort in knowing that there is some recourse to address problems.

How to Communicate?

Overview

Stakeholders proposed several characteristics of communications to ensure that they were effective (Table 4).

Table 4. Characteristics of communications: description and examples of stakeholders' perspectives.

Characteristic of communication	Description	Exemplary citations of different stakeholders extracted from reviewed studies
Frequency [11, 18,33,36,38,49, 59,74,76,78,79, 81,100,105,125, 140,156,171-173]	<ul style="list-style-type: none"> Periodically, on an ongoing basis [33,36,38,74,76,78,79,81,140,156, 171,172] Linked to health care encounters [18,49,59,100,125] Upon request [78,105] 	<ul style="list-style-type: none"> “The most appropriate approach would be to design consents and notices that are like that as well—real-time, updated, frequently communicating with you and letting you know not only how your data is going to be used and how it will be protected privacy and security wise... I think a consent information type notice should happen regularly [and] keep you engaged in understanding the continued use of this data” (regulatory expert opinion regarding unregulated mobile app research [81]). “At least once a year. If nothing else, you know what is going on” (patient from a US Veterans Affairs facility [77]). “Maybe every half a year, or maybe even once a month [...]. It would be good every six months to get follow-up information” (2 members of the public [79]). “I’d like to be notified anytime anybody accesses my medical records. Even if it’s my primary care physician... I’d either be notified through email or whenever you log on... When you log on, you should be able to see a list of everybody who’s accessed your file” (patient [74]). “What does the quantity look like? I mean, if we are getting 10 emails a day, we might get annoyed” (member of the public [11]).
Associated support [11,19,32, 36,40,41,43, 45-48,50-53,56, 59,68,69,73,74, 76,78,79,81-83, 85,86,88,90,92, 95,100,103,105, 108,114,123,127, 129,132,133,138, 139,141,143,150-153, 155,158,160,165, 171,172,174-183]	<ul style="list-style-type: none"> Support that is electronic [73,74,76,78,81,88,143,180] Support that is delivered by mail [32,59,78,158] Support that is face-to-face [43,59,79,83,139,160,175,177] Support that is delivered through technology [48,52,152] Support that is delivered traditionally [41,43,47,59,105] Support that is delivered through social media [88,108,132,172] Support that is delivered through emails [138,158,171] Support that is delivered through newsletters [69,83,171] Support that is delivered through academic and health institutions [40,85,108,132,141] Support that is delivered through health [11,19,32,40,45,50,56,59, 68,69,76,82,83,100,123,143,150-153, 155,165,174,176-178,183] or research [123,177] professionals and peers [51,76,92,129,132,143,153] <p>Examples of technological supports include the following:</p> <ul style="list-style-type: none"> Patient portals [114,123,158,172,175] Public databases [53,158] Websites [41,53,69,83,88,90,127,138,141,181] Web-based FAQ^a section [88,103] Short videos [11,36,103,132,174,179] Mobile apps [73,86] <p>Examples of physical support included the following:</p> <ul style="list-style-type: none"> Posters [36,95,123,176,181] Flyers [46,53,59,132,133,176] 	<ul style="list-style-type: none"> “They [care providers] all use very strange words and it’s in one ear and out the other, and then when you get home, you have forgotten. But now, you can check again and you can look it up on the internet” (patient in conditions of vulnerability [175]). “I like how it’s (the electronic version) broken up so it’s easier to read. It’s less intimidating upon first glance than a packet of paper” (patient [73]). “If someone is telling face-to-face, it’s easier to motivate or convince the person. But if it’s some odd papers, sometimes you just skip the part that you didn’t need” (member of the public [79]). “Having a website is cost-effective because if people are interested they can go on it and have a look; if they’re not then they don’t have to. Leaflets and things like that, I think, are expensive and unnecessary because 95 per cent of them will just end up at the bottom of a bird cage” (member of the public [105]). “Well then you’d feel that you were doing something that was very worthwhile wouldn’t you, you’d think you were part of it, instead of just wondering what’s going to happen, even a website we could come on and just see what’s happening, to keep us updated” (biobank participant [83]). “[I]f there’s sort of a portal to a web-based feedback that’s easy for physicians to use in the little time they have during the day, that would be good” (oncologist familiar with rapid learning systems [123]). “For me, it [consent portal]’s a must because it’s kind of a control thing. I would be able to see who’s using it and why” (member of the public [11]). “And if it works for me, I can point [to] my other nephews and cousins and everybody else and say: ‘Go try this out. Go see these people.’ Because I want to be a spokesman and I will say, you know, ‘This is what works. This is how I combat this or that.’ And I’d have an avenue to say, ‘Hey, go try that program out’” (patient from an Indigenous community [92]). “[...] To perceive leaflets as light reading while awaiting their appointments: ‘People pick them up and read them while they are waiting and then put them back’” (patient [59]). “The problem I have is that not everybody has a cell phone. Not everybody has access to electronics, and probably the people who are most underserved are those people. Probably the socioeconomic group odds are they don’t have money to buy these fun things, or they don’t have the education to be able to use them. So they’re left in the dark, and they’re probably the ones that are most easily taken advantage of” (oncology patient [114]).

Characteristic of communication	Description	Exemplary citations of different stakeholders extracted from reviewed studies
Format [33,55,56,65,72,73,91,103,116,127,160,167,174-176,184,185]	<ul style="list-style-type: none"> Brief [127,160,167,174,176] Interpreted [55,127,175,176,184,185] Layered to permit little or more information [33,56,73,91,103,127] 	<ul style="list-style-type: none"> “If someone can answer, ‘Here’s where it’s stored, here’s how we use it’ in simple ways, not this 30-page agreement. Very simply [...]” (early adopter of eHealth technology [167]). “I sort of wish that I could provide some second bulleted point of one page that was like, ‘In plain language this is what you’ve just agreed to’” (researcher [127]). “The average person might not understand the meaning of all of [the results] so [results] would have to be returned in a format they can relate to” (researcher [127]).
Wording [11,31,32,39,44,46,51,54,56,63,65,70,72,73,76,79,81,87,92,93,99-101,103,105,111,114,127,130-132,134,139,143,160,167,172,173,175,176,186-188]	<ul style="list-style-type: none"> In accessible, plain language [44,46,56,65,72,73,76,79,81,87,92,93,99,100,103,105,111,114,127,130,132,134,139,160,167,173,175,176,188] Attention to levels of literacy [11,32,56,131,172,176,187] Use of mother tongue [51,70,92,188] Attention to special needs [101,143,176] Attention to cultural competency [51,92,131,186] Attention to tone [54,103] With explicit language [39,65,81,103,187], use of visual supports [103,176] and examples [103,176] Impartial and uncensored [31] 	<ul style="list-style-type: none"> “Researchers should state exactly what is being done with data and make it simple for people to understand” (citizen council member [93]). “This [Health Care Information Directive] is too busy, it’s too much. If I’m sick, I friggin’ don’t want to be bothered with it... Look at this. English is my first language. How would somebody whose mother tongue is something other than English? [sic] It’s too complicated” (senior citizen [100]). “In terms of getting the information out to Alaskan Native people, just providing this in a very clear manner about what it is, what it means, what it can do for our system, what it can do for them individually. So, I think that, again, transparency is really huge” (health care provider [92]).

^aFAQ: frequently answered questions.

Communication Approaches That Are Ongoing and Varied

To raise awareness and education, continuous communication methods (Table 4, row 1) as well as citizen forums were deemed appropriate strategies by all stakeholders, including patients and members of the public, as the best ways to reach all citizens “[...] before they actually become patients” [42]. For generic content for the purpose of informing with regard to a particular data set or data use or for specific content, mixed strategies with recourse to traditional media, social media, websites, patient portals, phone lines, posters, and flyers were proposed, again with the intention of reaching as many individuals as possible (Table 4, row 2). There was a concern that certain groups of citizens may be excluded if web-based communication is the only approach used [73,105,114]. Others favored information on demand as a cost-effective way for individuals to obtain the information needed [105]. Some underlined the virtue of centralizing the information to avoid being overwhelmed by the amount of information on the web [33,105,129]. Bernaerdt et al [175] outlined obstacles to the use of e-portals by “susceptible patients” and proposed recommendations for their design, an initial face-to-face encounter, and ongoing education.

Frequency

There was no consensus on the appropriate frequency, but the concept of continuous or periodic communication was frequently raised, with some practical suggestions to link to other communications and health encounters (Table 4, row 1). Overby et al [41] found that 51% of respondents stated that regular

updates increased their likelihood of participating in a biobank [41].

Associated Support

Many stakeholders emphasized providing support around the communications (Table 4, row 2). Examples of institutional and technological support were proposed but the need to be able to converse directly with a person, whether a peer, a health professional, or a research coordinator, was deemed important. Overall, stakeholders, including the European Commission [203], encouraged person-centered approaches to communications [51,74]. Rake et al [179] presented a model of personalized consent flow *as a starting point to meet all requirements for sharing personally collected and controlled health data for research* [179]. In the context of biobanking, Dirks et al [78] emphasized the importance of not making assumptions regarding preferences about communication but to “[...] instead consider using communication strategies that use iterative inquiry to learn about and engage communities in which they [researchers] wish to conduct research.”

Format

Ideal formats of communications were deemed to be brief, accessible to all, notwithstanding impairments such as visual handicaps, and included an interpretation of results (when applicable) (Table 4, row 3). Of note, 43% of blind or low-vision respondents to a national survey exploring the views of persons with disabilities about participation and barriers to participation in precision medicine research agreed with the statement, “information about medical research is not accessible to me” [101].

In the context of eHealth, it was suggested that we need to move away from traditional terms and conditions that are infrequently read by users. The latter were reported to not be written in a way to engage people as it often does not use basic language or sufficient concise content, but at the same time, not explicit enough on certain aspects considered essential by the participants [65,167]. An interesting example involving layered communication was proposed in the context of communicating with patients about software to enhance privacy in secondary database research involving record linkages [103]. This strategy, which uses expandable text and on-demand definitions, allows to provide information to those who want it while reducing on-screen text for those who feel overwhelmed [103].

Wording

Stakeholders suggested considerable advice on the question of wording (Table 4, row 4). Nelson et al [176] proposed a whole framework to communicate health data that emphasizes the importance of plain language devoid of medical jargon and provide contextual information to assist interpretation.

Communications should be explicit and consider special needs, native language, cultural competencies, tone, and level of literacy. Some have suggested dedicated resources to a phone line for direct access to information and explanations [53]. Patients [103] and other stakeholders [176] proposed the use of visual aids and inclusion of examples. Of interest, we came across a single stakeholder (member of a citizen jury) who raised concerns about the choice of certain terms and their legal implications [97].

When to Communicate: Situations Where Communication Becomes Necessary

Overview

When discussing the secondary use of health data, stakeholders often referred to situations in which they considered communication necessary (Table 5). The 4 categories of situations that could or should trigger a communication, reaffirm themes that emerged around the types of information desired (Tables 2-3) and foreshadow, to a certain extent, the ideal format (Table 4).

Table 5. Situations where communication becomes necessary: description and examples of stakeholders' perspectives.

Situations	Description	Exemplary citations of different stakeholders extracted from reviewed studies
Before the reuse of data [40,53,59, 67,74,80,81,86, 91,97,108,138, 144,145,152,158, 166,167,189-192]	<ul style="list-style-type: none"> To exert control on the secondary use of one's data [40,67,81,91,152,189,190,192] When the reuse involves the private sector [53,81,97,158,191] When a minor participant reaches the age of majority [67,189] When the data are sensitive [53,59,74] In the context of public health emergencies when consent is not required [108] 	<ul style="list-style-type: none"> "The most appropriate way is to inform the patient every time their data moves to the researcher or moves for a purpose and give them a chance to opt out or opt in each time. It may not be the most ideal for the company, but it's much more ideal for the patient" (expert opinion regarding unregulated mobile app research [81]). "I don't like it [one-time broad consent]. That's just me because I mean it's just like you sign the form once and you never see it again and then later on in life it ends up biting you in the ass cause well you signed the form once and you never saw it again. But someone goes out and dusts off your records and says, 'Hey look here.' I'm like, 'Well Goddam I guess I did sign it.' And you can't do anything about it. There's no option" (patient [40]). "I'm down with that... People can do whatever they want with our data... But what you're trying to tell me is you're now doing research that will put my name back on the data I gave you. In a way, you're not just doing research on my data. You're doing research on my data that will add data to my data that I didn't give you for a reason" (early adopter of health technology [167]). "In an ideal world I would include that a company, when they share and sell the data, would need to have a site that users could access to see with whom their data has been shared" (patient advocate regarding unregulated mobile app research [81]).
When individual results become available [51,54, 56,69,81,83,91, 98,144,193]	<ul style="list-style-type: none"> Results that are actionable [81,83,91,144] or not [56] Incidental findings with clinical relevance [54,193] or not [193] 	<ul style="list-style-type: none"> "Yes, definitely. The reason that this [cardiac arrest] doesn't bother me anymore in daily life is that the blood clot was taken out and they explained to me what had happened. What had gone wrong in my body. I could see it clearly on the monitor during the catheterisation. So you finally know what it was that made you feel unwell. That was really nice. So in ninety percent of the cases I'd say, 'tell me everything you can find about me, please'" (patient survivor of cardiac arrest [54]). "Well, I was pleased with it and I'm a bit like, that's one of the incentives for me to go in for I was interested to know how well I was and I was also interested to know about my cholesterol as well because my father had really, really high cholesterol and I've never had mine done, so I thought, 'well, that's a way to find out what mine is'" (biobank participant [83]). "I would have liked to have had a more detailed summary than we actually got. I think there were other things that they could have given and, for example, had there been any major medical problems I think it would have been good if they'd have pointed those out at some stage or other" (biobank participant [83]). "It may not be a guarantee that this will happen, but one of the key issues in a disease such as this... is early identification and spurring people to action. Melanoma is probably one of the cancers that kills a lot of people, I would imagine because they aren't aware of it and don't act early enough... So, if he has an algorithm that's more than 50% accurate, it's imperative that he let the individuals be aware" (patient advocate regarding unregulated mobile app research [81]). "If that gentleman thinks he's the carrier for something and he's not, he needs to know that" (genetics specialist on the subject of false paternity [193]).
When new global research results become available [76,78,98,129, 144,156,158,186]	<ul style="list-style-type: none"> To maintain trust and community engagement [144,186] Research conclusions may influence a person [98,129] or a community's actions [76,186] 	<ul style="list-style-type: none"> "[...] A lot of the researchers were always promising verbally that they were going to share the information with you and... more than half the time they never see that the results of the data after they leave your community. That's part of the reason why a lot of the Natives in small communities don't trust the researchers" (member of an Indigenous community [144]).
In the occurrence of a breach in confidentiality [52,73,97,164]	N/A ^a	<ul style="list-style-type: none"> "If my health information is compromised, how will I be informed?" (patient [73]). "If you do the wrong thing, you should face the consequences... then maybe they won't do it again" (citizen jury [97]). "Certainly, there is reportability back to the Institutional Review Boards [IRB]. There is probably reportability back to our audit committee of our board, which oversees compliance in Health Insurance Portability and Accountability Act [HIPAA] at the very minimum, depending if it's identified... I mean, it could go all the way out to notification... Certainly notification to the patient if it's identified, but also perhaps the government agencies" (institution compliance officer [52]).

^aN/A: not applicable.

Before the Reuse of Data

In the context of data sharing, many patients (67%) believed that they should be informed before their data were reused [86,192], and this feeling was enhanced when the data were viewed as sensitive [53,74] (Table 5, row 1). Sharing data with the private sector raised concerns [119,194]. In the context of Canadian citizens participating in a week-long dialogue, “[...] 56% of participants indicated that their tissue samples should never be used or that they must always be asked if profit is involved” [53]. Another interesting situation is that of minor participants who may want to be informed of past, current, and future data uses at the time of their majority [67,189].

When Individual Results Become Available

The return of individual results and the management of clinically important incidental findings have been largely discussed in the context of biobanking, but appear important in other contexts, including administrative databases [54,97], digital data [153], and mobile apps [81]. Some stakeholders highlighted how these communications—whether generic when global research results become available or specific when new individual research results become available—were deemed important to them as they would permit them to act on their own health or the health of their communities (Table 5, row 2). Finally, a few stakeholders deemed it necessary to communicate in the case of a breach of confidentiality.

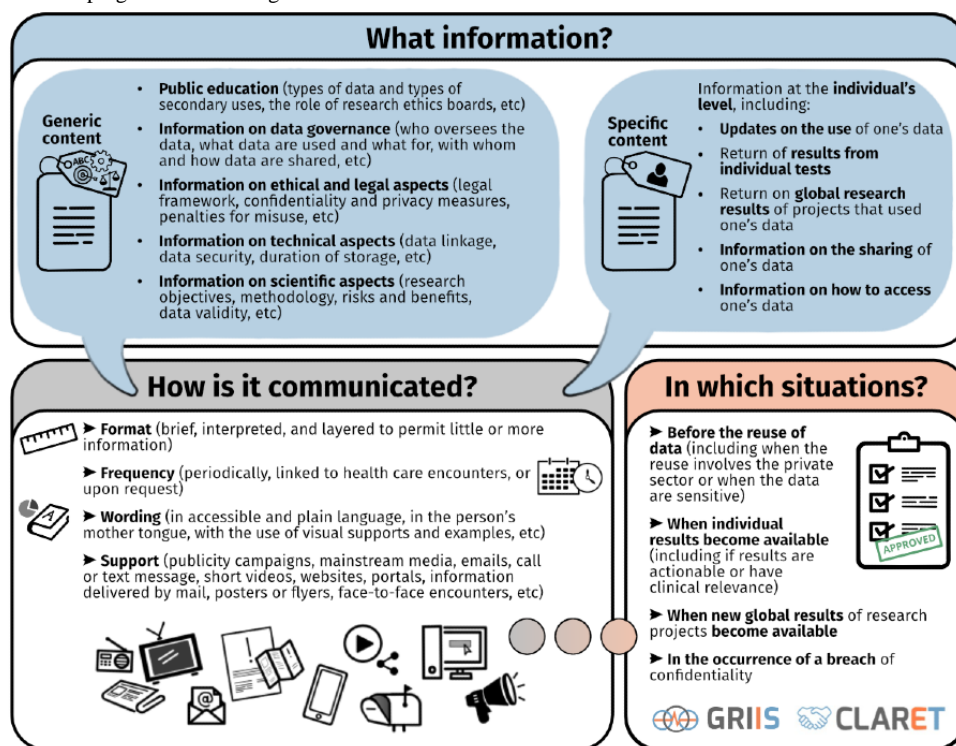
Discussion

Principal Findings

This scoping review presents an extended analysis of the literature on patients, public, and other key stakeholders’

perspectives on transparency and secondary use of health data. It reports findings from 178 studies with various designs published over the past 2 decades. This extensive work is the first to map the views of a broad range of stakeholders on what information should be communicated to data contributors and how and in what situations to ensure transparency with the secondary use of health data. Figure 2 summarizes the findings of this study. There was a major overlap in the perspectives of different stakeholders. Some groups expressed opinions that reflected specific needs, such as data sovereignty in the context of Indigenous community data or access to results for patients with rare disorders. Overall, communication was deemed crucial for many purposes, including educating patients and members of the public on potential benefits, giving some control over data use as a form of reciprocity and as a condition to build and maintain trust. Elements that should be communicated include generic content, such as governance and regulatory frameworks, scientific aims, potential future uses of the data, and specific content that is relevant to each person with regard to the use of their data. Regarding methods of communication, broad approaches were generally favored, such as nationwide publicity campaigns, mainstream and social media for generic content, and mixed approaches for specific content, including websites, patient portals, and face-to-face encounters. Patients and members of the public rarely specified on whom the onus for these communications would fall, but we can imagine a shared responsibility according to intent and means between governmental, national, health care organizations, other large data custodians, and, to a lesser extent, individual researchers. Content should be customized to the individual as much as possible with regard to the length, avoidance of technical terms, cultural competence, and level of detail.

Figure 2. Summary of the scoping review’s findings.



Interpretation of Findings

At this moment, in Western societies, sharing both generic and specific content seems necessary to achieve the goals of raising awareness, creating and maintaining trust by respecting the *moral concerns of donors* [110], and addressing the specific information needs of populations that have experienced racism and research violations [166,186,190]. Raised awareness and education are fundamental for members of the public to understand the legitimacy of various secondary uses of health data [58,79,134,163,194,195]. However, the data suggest that the current knowledge deficit is important [196,197]. In the international survey by Milne et al [85], providing transparent information about who will benefit from access to genomic data was the most important measure for increasing trust. There is an ongoing perceived need for control over the secondary use of health data and an aspiration for *greater equity in the science-public relationship* [31]. These findings confirm the conceptual framework by Brall et al [147] of individual willingness to participate in personalized health research and emphasize certain elements. The framework identified 20 elements pertaining to attitude, motivation, utility of results, data sharing and use, data management, and data governance that can have an impact on individual willingness. All these elements are presented in our review. Their relative importance could evolve with society's greater understanding of data, measures taken to make their reuse secure, and confirmation of the benefits of secondary use. Achieving the objective of transparency needs to address its various facets whether it is "informational transparency" defined by Aitken et al [31] as "requiring disclosure of information on which decisions are based," "participatory transparency" defined as "enabling public participation in decision-making processes," and "accountability transparency" defined as "decision-makers are held accountable." Any step toward greater communication and transparency should be carefully considered to ensure relevance and quality and decrease the risk of negative backlash [204].

A narrative review of the literature highlights the fact that social licenses for data-intensive health research cannot be assumed [205]. Trust and its absence had a considerable impact on the acceptance of the secondary use of health data without specific consent [136,191,198]. Muller et al [206] emphasized the merits of using the concept of social license as a reference for ethical governance and highlighted the strategic importance of dialogue with patients and members of the public. Research is ongoing to define what secondary uses of health data are within a social license and how perspectives could change with greater transparency [207]. On the basis of 8 focus groups with Canadian members of the public, Paprica et al [194] concluded that "[r]esearchers and organizations that hold health data should engage with members of the public to ensure that research is aligned with social license, particularly where there is private-sector involvement." These findings are also reflected in a similar study of deliberative focus groups conducted with United Kingdom citizens [208]. Furthermore, we would do well to not assume and rather gather more evidence to support the idea that transparency and trust will necessarily go hand in hand [20].

Reciprocity was also a transversal theme in this review and is likely a foundation on which to build this common understanding with different communities and populations. Indeed, Sexton et al [34] linked trust and reciprocity and raised the concern that "[f]aceless processes of governance are increasingly foregrounded over traditional relational bonds." Hobbs et al [83] explored the privacy-reciprocity connection, whereby participants attached certain conditions to their research donations. Patient engagement is another form of reciprocity that could increase trust [31]. Finally, reciprocity from the private sector appeared to be an important condition for sharing health data [136,191].

The return of individual results, particularly if perceived as potentially actionable, was a commonly cited example of a specific communication that patients and members of the public wanted, and this was substantiated by other research [209,210]. For some but not all, it was a motivation to donate health data, including genomic data [199]. What is less clear is whether, in the absence of the return of individual results, the need for information could be satisfied by communication on aggregated or global research results.

We also tried to distinguish whether individuals wished to receive specific communication about the secondary use of information by a single research project or by a group of projects with similar features. However, that distinction was not clearly present in our analysis. It could be interesting to confirm that an intermediate level of information is linked to the category of projects (eg, academic research, research with genomic data, and research with a private partner) that may or is using the data could meet individuals' need for information without excessive use of resources [192]. This would also align well with a metac Consent model, a promising dynamic approach to information and consent in the context of LHS [11].

There will be no one size fits all—some individuals wanted regular communications by varied means and at specific times, for example, each time their data were used, whereas others wished for basic information to be available on demand so that resources can be allocated elsewhere. Individual factors, including age, ethnicity, gender, education, general and scientific culture, curiosity, and motivations to participate in research, were key to explaining the variety of views on the subject [56,59,83,151,158,166]. Biobank participants, for example, may have a more altruistic outlook and a reduced need for the return of information than members of the public at large who are less aware of the risks and benefits of research. It will also be important to pay attention to the "unheard voices" of people who are marginalized in society [169]. Public deliberation is an interesting approach to better understand specific population needs and preferences for notifications about data sharing [114]. Any communication strategy will need to be patient-centered and modifiable so that low information seekers are not overwhelmed by unwanted communication, and high information seekers can equally meet their needs [11,69]. Communications should also be adapted to the needs of people with disabilities, especially considering that technology is creating an information accessibility gap as it tends to replace face-to-face communication [101]. Interesting models of communication include the frequently asked questions section

that provides layered information so that an individual could obtain as much or as little information as desired [103] and the OPT-IN framework by Nelson et al [176] “[...] to help guide communicators with selecting and presenting data to lay audiences, taking into account the broader communication perspective.” Guidelines on how to discuss the protection and use of personal health information would also be welcome [59].

Findings in Relation to Broader Context

There are other noteworthy initiatives to help us pave the way forward and find a balance between information needs, trust, and societal benefits from the secondary use of health data [200]. We would like to highlight 4 key features: patient or public engagement, harmonization of policies, the importance of user-centered informational tools, and innovations in data security.

First, transparent governance and patient engagement are increasingly being proposed as important avenues toward social license. Paprica et al [87] proposed the minimal specifications for data trust. Participatory governance is a key concept, as exemplified in the Academic Research Network of Diabetes Action Canada [72], the Research Data Alliance COVID-19 Working Group guidelines [201], and in 1 of the 7 recommendations from the work by Courbier et al [76] with patients with rare diseases. Participatory governance is also necessary to respect the Principles for Indigenous Data governance [201].

Second, the adoption of coherent policies and practices can help harmonize different initiatives and reduce risks, such as privacy breaches [44]. National or institutional standards such as Quebec’s Fonds de Recherche Standards for Data Access Centers [211], New Zealand’s integrated data infrastructure [166], and the United Kingdom’s data registry standard [212] are a few examples of initiatives that can serve as models.

Third, educational tools will be required to raise awareness among all stakeholders, with a focus on members of the public and tailored to specific populations. Such large-scale initiatives could address the frequently expressed need for information to help individuals control their use of data. Indeed, studies have demonstrated that once informed of regulatory safeguards, presented with conditions around use [6], informed of impacts [213], or sensitized to logistic hurdles, opinions regarding individual consent and control can shift.

Fourth, we should build on existing communication strategies. The Health Care Information Directive is an example of a patient decision aid that aims to delineate the level of health information that an individual is willing to share [100,214]. Caine et al [74] derived 6 implications for the design of a patient-centered tool to allow individual choices in the disclosure of health data from patient interviews. In their systematic review of the design of patient aids, Vaisson et al [215] proposed a user-centered design framework that could help design future aids to track the secondary use of one’s health data. The proposed concept interface enables contextual control by allowing patients to set their privacy levels in the context of viewing events within an electronic health record. Fagerlin et al [216] proposed 10 pragmatic recommendations to help patients make decisions

when faced with complex information on risks and benefits that could be applied to making decisions about data sharing. On a more theoretical level, Zikmund-Fisher [217] proposed a standard taxonomy of risk concepts that could inform or evaluate future communications. Riso et al [70] outlined a framework with 6 core values to improve the ethical standards of data-sharing platforms. For example, the GA Registry [218] is patient-led and permits large-scale data sharing while letting users decide which data sets to share and with whom. Exemplary projects and patient portals include the tailored, ongoing communication of the CHRIS longitudinal study [202], NIH-funded *All of Us* Research Program [219], *Connect Care* (Canada) [220] that allows bidirectional interaction with the patient, *Sundhed* (Denmark) [221], and *Health data hub* (France) [222].

Finally, ongoing innovations in data security will be important to enhance privacy and trust in all these initiatives. Examples include CrowdMed, a blockchain approach proposed by Shah et al [180] and MiNDFIRL, a software to enhance privacy in secondary database studies [103].

Limitations

Our search yielded most articles originating from North America and Europe and documenting Western contexts and attitudes; therefore, our review may not entirely represent other societies. In addition, although we cited research conducted with stakeholders from Indigenous communities, we cannot conclude that the views collected are representative of all Indigenous communities. Furthermore, many earlier articles focused on research conducted in the context of biobanking. We restricted our analysis to articles that explored stakeholder perspectives with a focus on the future use of samples or data. During thematic analysis, we were able to conclude that many of the perspectives overlapped with research conducted in other contexts, such as administrative databases, data mining, and mobile app. This suggests that for the person concerned by the secondary use of health data, there are similarities between the research contexts of biobanking and newer contexts.

Conclusions

This scoping review highlights the diversity and extent of patient and public expectations regarding information on the secondary use of health data. It also attests how and in which situations the communication of different types of information could contribute to the objective of greater transparency. These findings suggest that governing bodies should actively invest in widespread and targeted activities to increase public awareness and understanding about the secondary use of health data. Modern societies would do well to foster a culture of information and health literacy, which in turn is necessary for individual empowerment in the context of health care. Indeed, our results highlight the importance of patient, citizen, and community engagement in different secondary uses of health data [104]. This is particularly true for some populations such as Indigenous communities that have developed their own models of data governance [223].

Future studies should consider building on existing models to develop thoughtful strategies for communicating with the

secondary use of health data. This review did not identify resources specifically considering the LHS context; therefore, the impact of such a framework on the desires of patients and members of the public remains to be explored. To support the implementation of LHSs in Quebec (through a transparency portal), the next steps would be to validate some of the results with patients and members of the public, including the following: (1) the need for both types of content (generic and specific); (2) the level of generic content to meet information needs and foster and sustain trust; and (3) the resulting most appropriate format considering resource use and development of web portals to support LHSs [224]. Other research could also validate how we can match actual citizen and patient needs with congruent types of knowledge and informational tools (Table

2 in the study by Zikmund-Fisher [217]), and how the personalization of communications meets the demands of different regulatory bodies, for example, the recommendations of the European Commission [203]. Another important question is whether transparency leads to unexpected outcomes, such as desensitization and “systematic exploitation” [111]. Finally, these strategies should be evaluated to ensure that they reach their objectives, notably with regard to transparency and even improving health outcomes at the individual and system levels. Beyond just informing members of the public on the secondary use of their data, we should aim to foster a culture in which all citizens are given tools to participate in their health care and determine research priorities [139].

Acknowledgments

The authors would like to express their sincere thanks to Professor Daniel Caron and Emmanuel Bilodeau for their critical review of the manuscript draft. They also want to thank Dominique Wolfshagen for creating [Figure 2](#), Timothy Bédard for his important work in the coding of the articles, and Denis Boutin and Karina Prévost for their thoughtful and wise recommendations as patient partners in the research program. This work was supported by J-FE personal fundings.

Data Availability

The data generated and analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

AC, J-FM, AB, RD, and J-FE participated in the identification of the research questions, conception and design of this scoping review, and data analysis and interpretation. RD, FL, AC, and J-FM participated in the study selection, data extraction, and interpretation. AC drafted the paper, but all authors critically revised it for important intellectual content. All authors granted final approval for the version to be published and take accountability for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

PRISMA-ScR Checklist.

[\[DOCX File , 79 KB-Multimedia Appendix 1\]](#)

Multimedia Appendix 2

Research strategies.

[\[DOCX File , 24 KB-Multimedia Appendix 2\]](#)

Multimedia Appendix 3

Characteristics of the articles included in the scoping review.

[\[DOCX File , 62 KB-Multimedia Appendix 3\]](#)

References

1. Enticott J, Johnson A, Teede H. Learning health systems using data to drive healthcare improvement and impact: a systematic review. *BMC Health Serv Res* 2021 Mar 05;21(1):200 [[FREE Full text](#)] [doi: [10.1186/s12913-021-06215-8](https://doi.org/10.1186/s12913-021-06215-8)] [Medline: [33663508](https://pubmed.ncbi.nlm.nih.gov/33663508/)]
2. Tilahun B, Teklu A, Mancuso A, Endehabtu BF, Gashu KD, Mekonnen ZA. Using health data for decision-making at each level of the health system to achieve universal health coverage in Ethiopia: the case of an immunization programme in a low-resource setting. *Health Res Policy Syst* 2021 Aug 11;19(Suppl 2):48 [[FREE Full text](#)] [doi: [10.1186/s12961-021-00694-1](https://doi.org/10.1186/s12961-021-00694-1)] [Medline: [34380496](https://pubmed.ncbi.nlm.nih.gov/34380496/)]

3. Cascini F, Santaroni F, Lanzetti R, Failla G, Gentili A, Ricciardi W. Developing a data-driven approach in order to improve the safety and quality of patient care. *Front Public Health* 2021 May 21;9:667819 [FREE Full text] [doi: [10.3389/fpubh.2021.667819](https://doi.org/10.3389/fpubh.2021.667819)] [Medline: [34095071](https://pubmed.ncbi.nlm.nih.gov/34095071/)]
4. Fanelli S, Pratici L, Salvatore FP, Donelli CC, Zangrandi A. Big data analysis for decision-making processes: challenges and opportunities for the management of health-care organizations. *Manage Res Rev* 2022 May 10;46(3):369-389. [doi: [10.1108/mrr-09-2021-0648](https://doi.org/10.1108/mrr-09-2021-0648)]
5. Madhusoodanan J. Health data for all. *Nature* 2022 May 03;605(7908):182-183. [doi: [10.1038/d41586-022-01205-0](https://doi.org/10.1038/d41586-022-01205-0)] [Medline: [35505184](https://pubmed.ncbi.nlm.nih.gov/35505184/)]
6. Cumyn A, Dault R, Barton A, Cloutier A, Ethier J. Citizens, research ethics committee members and researchers' attitude toward information and consent for the secondary use of health data: implications for research within learning health systems. *J Empir Res Hum Res Ethics* 2021 Jul;16(3):165-178 [FREE Full text] [doi: [10.1177/1556264621992214](https://doi.org/10.1177/1556264621992214)] [Medline: [33710932](https://pubmed.ncbi.nlm.nih.gov/33710932/)]
7. Ghafur S, Van Dael J, Leis M, Darzi A, Sheikh A. Public perceptions on data sharing: key insights from the UK and the USA. *Lancet Digital Health* 2020 Sep;2(9):e444-e446. [doi: [10.1016/s2589-7500\(20\)30161-8](https://doi.org/10.1016/s2589-7500(20)30161-8)]
8. Kim K, Joseph J, Ohno-Machado L. Comparison of consumers' views on electronic data sharing for healthcare and research. *J Am Med Inform Assoc* 2015 Jul;22(4):821-830 [FREE Full text] [doi: [10.1093/jamia/ocv014](https://doi.org/10.1093/jamia/ocv014)] [Medline: [25829461](https://pubmed.ncbi.nlm.nih.gov/25829461/)]
9. Kelley M, James C, Alessi Kraft S, Korngiebel D, Wijangco I, Rosenthal E, et al. Patient perspectives on the learning health system: the importance of trust and shared decision making. *Am J Bioeth* 2015;15(9):4-17 [FREE Full text] [doi: [10.1080/15265161.2015.1062163](https://doi.org/10.1080/15265161.2015.1062163)] [Medline: [26305741](https://pubmed.ncbi.nlm.nih.gov/26305741/)]
10. Willison DJ, Schwartz L, Abelson J, Charles C, Swinton M, Northrup D, et al. Alternatives to project-specific consent for access to personal information for health research: what is the opinion of the Canadian public? *J Am Med Inform Assoc* 2007;14(6):706-712 [FREE Full text] [doi: [10.1197/jamia.M2457](https://doi.org/10.1197/jamia.M2457)] [Medline: [17712084](https://pubmed.ncbi.nlm.nih.gov/17712084/)]
11. Cumyn A, Barton A, Dault R, Safa N, Cloutier A, Ethier J. Meta-consent for the secondary use of health data within a learning health system: a qualitative study of the public's perspective. *BMC Med Ethics* 2021 Jun 29;22(1):81 [FREE Full text] [doi: [10.1186/s12910-021-00647-x](https://doi.org/10.1186/s12910-021-00647-x)] [Medline: [34187453](https://pubmed.ncbi.nlm.nih.gov/34187453/)]
12. Caron D, Bernardi S, Nicolini V. L'acceptabilité sociale du partage des données de santé : revue de la littérature. Canada: Dépôt légal Bibliothèque et Archives nationales du Québec; Nov 2020.
13. Limb M. Controversial database of medical records is scrapped over security concerns. *BMJ* 2016 Jul 07;354:i3804. [doi: [10.1136/bmj.i3804](https://doi.org/10.1136/bmj.i3804)] [Medline: [27387682](https://pubmed.ncbi.nlm.nih.gov/27387682/)]
14. Garrety K, McLoughlin I, Wilson R, Zelle G, Martin M. National electronic health records and the digital disruption of moral orders. *Soc Sci Med* 2014 Jan;101:70-77. [doi: [10.1016/j.socscimed.2013.11.029](https://doi.org/10.1016/j.socscimed.2013.11.029)] [Medline: [24560226](https://pubmed.ncbi.nlm.nih.gov/24560226/)]
15. Wakabayashi D. Google and the university of Chicago are sued over data sharing. *New York Times*. URL: <https://www.nytimes.com/2019/06/26/technology/google-university-chicago-data-sharing-lawsuit.html> [accessed 2022-10-14]
16. Abadie R, Heaney K. "We can wipe an entire culture": fears and promises of DNA biobanking among Native Americans. *Dialect Anthropol* 2015 Jun 7;39(3):305-320. [doi: [10.1007/s10624-015-9391-4](https://doi.org/10.1007/s10624-015-9391-4)]
17. Malboeuf M. Dossiers médicaux à vendre. *La Presse*. URL: <https://www.lapresse.ca/actualites/sante/201803/02/01-5155859-dossiers-medicaux-a-vendre.php> [accessed 2022-08-25]
18. Jagsi R, Griffith KA, Sabolch A, Jones R, Spence R, De Vries R, et al. Perspectives of patients with cancer on the ethics of rapid-learning health systems. *J Clin Oncol* 2017 Jul 10;35(20):2315-2323 [FREE Full text] [doi: [10.1200/JCO.2016.72.0284](https://doi.org/10.1200/JCO.2016.72.0284)] [Medline: [28537812](https://pubmed.ncbi.nlm.nih.gov/28537812/)]
19. Kisekka V, Goel S, Williams K. Disambiguating between privacy and security in the context of health care: new insights on the determinants of health technologies use. *Cyberpsychol Behav Soc Netw* 2021 Sep 01;24(9):617-623. [doi: [10.1089/cyber.2020.0600](https://doi.org/10.1089/cyber.2020.0600)] [Medline: [34152853](https://pubmed.ncbi.nlm.nih.gov/34152853/)]
20. Mabillard V, Caron DJ. Plus de transparence, plus de confiance? Regard critique sur un principe clé de bonne gouvernance et ses attentes. *Can Public Adm* 2022 Aug 30;65(3):482-496. [doi: [10.1111/capa.12487](https://doi.org/10.1111/capa.12487)]
21. Institute of Medicine Committee on the Learning Health Care System in America. A continuously learning health care system. In: *Best Care at Lower Cost The Path to Continuously Learning Health Care in America*. Washington, D.C., United States: National Academies Press; 2013.
22. Roundtable on Evidence-Based Medicine, Institute of Medicine. *The Learning Healthcare System Workshop Summary*. Washington, D.C., United States: National Academies Press; 2007.
23. Foley T, Horwitz L, Zahran R. Realising the potential of learning health systems. *The Learning Healthcare Project*. 2021 May. URL: <https://learninghealthcareproject.org/wp-content/uploads/2021/05/LHS2021report.pdf> [accessed 2022-10-11]
24. Lavis J, Gauvin F, Mattison C. Rapid synthesis: creating rapid-learning health systems in Canada 90-day response. *McMaster Health Forum*. 2018. URL: <https://www.mcmasterforum.org/docs/default-source/product-documents/rapid-responses/creating-rapid-learning-health-systems-in-canada.pdf?sfvrsn=4> [accessed 2022-10-11]
25. Faden RR, Kass NE, Goodman SN, Pronovost P, Tunis S, Beauchamp TL. An ethics framework for a learning health care system: a departure from traditional research ethics and clinical ethics. *Hastings Cent Rep* 2013;Spec No:S16-S27. [doi: [10.1002/hast.134](https://doi.org/10.1002/hast.134)] [Medline: [23315888](https://pubmed.ncbi.nlm.nih.gov/23315888/)]

26. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010 Sep 20;5:69 [FREE Full text] [doi: [10.1186/1748-5908-5-69](https://doi.org/10.1186/1748-5908-5-69)] [Medline: [20854677](https://pubmed.ncbi.nlm.nih.gov/20854677/)]
27. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Intl J Soc Res Methodol* 2005 Feb;8(1):19-32. [doi: [10.1080/1364557032000119616](https://doi.org/10.1080/1364557032000119616)]
28. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018 Oct 02;169(7):467-473 [FREE Full text] [doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850)] [Medline: [30178033](https://pubmed.ncbi.nlm.nih.gov/30178033/)]
29. Extending Your Literature Review With NVivo | Qualitative Data Analysis Resources. NVIVO. URL: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/resources/blog/extending-your-literature-review-nvivo-12-plus> [accessed 2022-10-17]
30. Carr D, Littler K. Sharing research data to improve public health: a funder perspective. *J Empir Res Hum Res Ethics* 2015 Jul 21;10(3):314-316 [FREE Full text] [doi: [10.1177/1556264615593485](https://doi.org/10.1177/1556264615593485)] [Medline: [26297752](https://pubmed.ncbi.nlm.nih.gov/26297752/)]
31. Aitken M, Cunningham-Burley S, Pagliari C. Moving from trust to trustworthiness: experiences of public engagement in the Scottish Health Informatics Programme. *Sci Public Policy* 2016 Oct;43(5):713-723 [FREE Full text] [doi: [10.1093/scipol/scv075](https://doi.org/10.1093/scipol/scv075)] [Medline: [28066123](https://pubmed.ncbi.nlm.nih.gov/28066123/)]
32. Goytia C, Kastenbaum I, Shelley D, Horowitz C, Kaushal R. A tale of 2 constituencies: exploring patient and clinician perspectives in the age of big data. *Med Care* 2018 Oct;56 Suppl 10 Suppl 1(10 Suppl 1):S64-S69 [FREE Full text] [doi: [10.1097/MLR.0000000000000786](https://doi.org/10.1097/MLR.0000000000000786)] [Medline: [30074954](https://pubmed.ncbi.nlm.nih.gov/30074954/)]
33. Jones KH, Ford EM, Lea N, Griffiths LJ, Hassan L, Heys S, et al. Toward the development of data governance standards for using clinical free-text data in health research: position paper. *J Med Internet Res* 2020 Jun 29;22(6):e16760 [FREE Full text] [doi: [10.2196/16760](https://doi.org/10.2196/16760)] [Medline: [32597785](https://pubmed.ncbi.nlm.nih.gov/32597785/)]
34. Sexton A, Shepherd E, Duke-Williams O, Eveleigh A. A balance of trust in the use of government administrative data. *Arch Sci* 2017 Oct 10;17(4):305-330. [doi: [10.1007/s10502-017-9281-4](https://doi.org/10.1007/s10502-017-9281-4)]
35. Terry A, Stewart M, Fortin M, Wong S, Kennedy M, Burge F, et al. Gaps in primary healthcare electronic medical record research and knowledge: findings of a pan-Canadian study. *Healthc Policy* 2014 Aug 29;10(1):46-59. [doi: [10.12927/hcpol.2014.23927](https://doi.org/10.12927/hcpol.2014.23927)]
36. Hepgul N, Sleeman KE, Firth AM, Johnston A, Teo JT, Bernal W, et al. In response to Ballantyne and Schaefer's 'Consent and the ethical duty to participate in health data research'. *J Med Ethics* 2019 May 07;45(5):351-352 [FREE Full text] [doi: [10.1136/medethics-2018-105271](https://doi.org/10.1136/medethics-2018-105271)] [Medline: [30617201](https://pubmed.ncbi.nlm.nih.gov/30617201/)]
37. O'Brien EC, Rodriguez AM, Kum H, Schanberg LE, Fitz-Randolph M, O'Brien SM, et al. Patient perspectives on the linkage of health data for research: insights from an online patient community questionnaire. *Int J Med Inform* 2019 Jul;127:9-17 [FREE Full text] [doi: [10.1016/j.ijmedinf.2019.04.003](https://doi.org/10.1016/j.ijmedinf.2019.04.003)] [Medline: [31128837](https://pubmed.ncbi.nlm.nih.gov/31128837/)]
38. Jao I, Kombe F, Mwalukore S, Bull S, Parker M, Kamuya D, et al. Involving research stakeholders in developing policy on sharing public health research data in Kenya: views on fair process for informed consent, access oversight, and community engagement. *J Empir Res Hum Res Ethics* 2015 Jul 21;10(3):264-277 [FREE Full text] [doi: [10.1177/1556264615592385](https://doi.org/10.1177/1556264615592385)] [Medline: [26297748](https://pubmed.ncbi.nlm.nih.gov/26297748/)]
39. Lemke A, Wolf W, Hebert-Beirne J, Smith M. Public and biobank participant attitudes toward genetic research participation and data sharing. *Public Health Genomics* 2010 Jan 15;13(6):368-377 [FREE Full text] [doi: [10.1159/000276767](https://doi.org/10.1159/000276767)] [Medline: [20805700](https://pubmed.ncbi.nlm.nih.gov/20805700/)]
40. Mamo LA, Browe DK, Logan HC, Kim KK. Patient informed governance of distributed research networks: results and discussion from six patient focus groups. *AMIA Annu Symp Proc* 2013;2013:920-929 [FREE Full text] [Medline: [24551383](https://pubmed.ncbi.nlm.nih.gov/24551383/)]
41. Overby C, Maloney K, Alestock T, Chavez J, Berman D, Sharaf R, et al. Prioritizing approaches to engage community members and build trust in biobanks: a survey of attitudes and opinions of adults within outpatient practices at the university of Maryland. *J Pers Med* 2015 Jul 28;5(3):264-279 [FREE Full text] [doi: [10.3390/jpm5030264](https://doi.org/10.3390/jpm5030264)] [Medline: [26226006](https://pubmed.ncbi.nlm.nih.gov/26226006/)]
42. Richter G, Borzikowsky C, Lesch W, Semler SC, Bunnik EM, Buyx A, et al. Secondary research use of personal medical data: attitudes from patient and population surveys in The Netherlands and Germany. *Eur J Hum Genet* 2021 Mar 01;29(3):495-502 [FREE Full text] [doi: [10.1038/s41431-020-00735-3](https://doi.org/10.1038/s41431-020-00735-3)] [Medline: [33005018](https://pubmed.ncbi.nlm.nih.gov/33005018/)]
43. Soni H, Grando A, Murcko A, Diaz S, Mukundan M, Idouraine N, et al. State of the art and a mixed-method personalized approach to assess patient perceptions on medical record sharing and sensitivity. *J Biomed Inform* 2020 Jan;101:103338 [FREE Full text] [doi: [10.1016/j.jbi.2019.103338](https://doi.org/10.1016/j.jbi.2019.103338)] [Medline: [31726102](https://pubmed.ncbi.nlm.nih.gov/31726102/)]
44. Watson K, Payne DM. Ethical practice in sharing and mining medical data. *J Inform Commun Ethics Society* 2020 Apr 17;19(1):1-19. [doi: [10.1108/jices-08-2019-0088](https://doi.org/10.1108/jices-08-2019-0088)]
45. Wetzels M, Broers E, Peters P, Feijs L, Widdershoven J, Habibovic M. Patient perspectives on health data privacy and management: "Where is my data and whose is it?". *Int J Telemed Appl* 2018;2018:3838747 [FREE Full text] [doi: [10.1155/2018/3838747](https://doi.org/10.1155/2018/3838747)] [Medline: [30631347](https://pubmed.ncbi.nlm.nih.gov/30631347/)]
46. The use of personal health information in medical research general public consultation. Medical Research Council. 2006. URL: <https://www.ipsos.com/sites/default/files/migrations/en-uk/files/Assets/Docs/Archive/Polls/mrc.pdf> [accessed 2022-09-27]

47. The attitude of the public to the use of patient information obtained from medical records by the national confidential enquiries. In: National Institute for Health and Care Excellence (NICE): NICE Citizens Council Reports. London, United Kingdom: NICE Citizens Council; 2004.
48. Westin A. How the public views privacy and health research. Institute of Medicine Committee. 2008. URL: https://www.ftc.gov/sites/default/files/documents/public_comments/health-care-delivery-534908-00001/534908-00001.pdf [accessed 2022-09-27]
49. Atkin C, Crosby B, Dunn K, Price G, Marston E, Crawford C, PIONEER Data Hub. Perceptions of anonymised data use and awareness of the NHS data opt-out amongst patients, carers and healthcare staff. *Res Involv Engagem* 2021 Jun 14;7(1):40 [FREE Full text] [doi: [10.1186/s40900-021-00281-2](https://doi.org/10.1186/s40900-021-00281-2)] [Medline: [34127076](https://pubmed.ncbi.nlm.nih.gov/34127076/)]
50. Darquy S, Moutel G, Lapointe A, D'Audiffret D, Champagnat J, Guerroui S, et al. Patient/family views on data sharing in rare diseases: study in the European LeukoTreat project. *Eur J Hum Genet* 2016 Mar 17;24(3):338-343 [FREE Full text] [doi: [10.1038/ejhg.2015.115](https://doi.org/10.1038/ejhg.2015.115)] [Medline: [26081642](https://pubmed.ncbi.nlm.nih.gov/26081642/)]
51. Tindana P, Depuur C, de Vries J, Seeley J, Parker M. Informed consent in genomic research and biobanking: taking feedback of findings seriously. *Glob Bioeth* 2020 Feb 23;31(1):200-215 [FREE Full text] [doi: [10.1080/11287462.2020.1717896](https://doi.org/10.1080/11287462.2020.1717896)] [Medline: [33343193](https://pubmed.ncbi.nlm.nih.gov/33343193/)]
52. Manion FJ, Robbins RJ, Weems WA, Crowley RS. Security and privacy requirements for a multi-institutional cancer research data grid: an interview-based study. *BMC Med Inform Decis Mak* 2009 Jun 15;9(1):31 [FREE Full text] [doi: [10.1186/1472-6947-9-31](https://doi.org/10.1186/1472-6947-9-31)] [Medline: [19527521](https://pubmed.ncbi.nlm.nih.gov/19527521/)]
53. Saxena N, MacKinnon M, Watling J, Willison D, Swinton M. Understanding Canadians' attitudes and expectations citizens' dialogue on privacy and the use of personal information for health research in Canada. Canadian Policy Research Networks. 2006. URL: https://oaresource.library.carleton.ca/cprn/43383_en.pdf [accessed 2022-09-27]
54. Bak MA, Veecken R, Blom MT, Tan HL, Willems DL. Health data research on sudden cardiac arrest: perspectives of survivors and their next-of-kin. *BMC Med Ethics* 2021 Jan 28;22(1):7 [FREE Full text] [doi: [10.1186/s12910-021-00576-9](https://doi.org/10.1186/s12910-021-00576-9)] [Medline: [33509184](https://pubmed.ncbi.nlm.nih.gov/33509184/)]
55. Cheung FY, Clatch L, Wolf SM, Clayton EW, Lawrenz F. Key expert stakeholder perceptions of the law of genomics: identified problems and potential solutions. *J Law Med Ethics* 2020 Mar 01;48(1):87-104 [FREE Full text] [doi: [10.1177/1073110520916997](https://doi.org/10.1177/1073110520916997)] [Medline: [32342788](https://pubmed.ncbi.nlm.nih.gov/32342788/)]
56. Hishiyama Y, Minari J, Suganuma N. The survey of public perception and general knowledge of genomic research and medicine in Japan conducted by the Japan Agency for Medical Research and Development. *J Hum Genet* 2019 May 6;64(5):397-407. [doi: [10.1038/s10038-019-0587-3](https://doi.org/10.1038/s10038-019-0587-3)] [Medline: [30842598](https://pubmed.ncbi.nlm.nih.gov/30842598/)]
57. Garrison NA, Barton KS, Porter KM, Mai T, Burke W, Carroll SR. Access and management: indigenous perspectives on genomic data sharing. *Ethn Dis* 2019 Dec 12;29(Suppl):659-668. [doi: [10.18865/ed.29.s3.659](https://doi.org/10.18865/ed.29.s3.659)]
58. Jao I, Kombe F, Mwalukore S, Bull S, Parker M, Kamuya D, et al. Research stakeholders' views on benefits and challenges for public health research data sharing in Kenya: the importance of trust and social relations. *PLoS One* 2015 Sep 2;10(9):e0135545 [FREE Full text] [doi: [10.1371/journal.pone.0135545](https://doi.org/10.1371/journal.pone.0135545)] [Medline: [26331716](https://pubmed.ncbi.nlm.nih.gov/26331716/)]
59. Shickle D, Carlisle J, Wallace S, Cork M, Beyleveld D, Bowns I, et al. Patient electronic record: information and consent (PERIC) public attitudes to protection and use of personal health information. White Rose Research Online. 2002. URL: <https://eprints.whiterose.ac.uk/128705/> [accessed 2022-09-27]
60. Adanijo A, McWilliams C, Wykes T, Jilka S. Investigating mental health service user opinions on clinical data sharing: qualitative focus group study. *JMIR Ment Health* 2021 Sep 03;8(9):e30596 [FREE Full text] [doi: [10.2196/30596](https://doi.org/10.2196/30596)] [Medline: [34477558](https://pubmed.ncbi.nlm.nih.gov/34477558/)]
61. Richter G, Borzikowsky C, Hoyer BF, Laudes M, Krawczak M. Secondary research use of personal medical data: patient attitudes towards data donation. *BMC Med Ethics* 2021 Dec 15;22(1):164 [FREE Full text] [doi: [10.1186/s12910-021-00728-x](https://doi.org/10.1186/s12910-021-00728-x)] [Medline: [34911502](https://pubmed.ncbi.nlm.nih.gov/34911502/)]
62. Demotes-Mainard J, Cornu C, Guérin A, participants of Giens XXXIV Round Table "Clinical research". How the new European data protection regulation affects clinical research and recommendations? *Therapie* 2019 Feb;74(1):31-42. [doi: [10.1016/j.therap.2018.12.004](https://doi.org/10.1016/j.therap.2018.12.004)] [Medline: [30642661](https://pubmed.ncbi.nlm.nih.gov/30642661/)]
63. Haga S, O'Daniel J. Public perspectives regarding data-sharing practices in genomics research. *Public Health Genomics* 2011 Mar 24;14(6):319-324 [FREE Full text] [doi: [10.1159/000324705](https://doi.org/10.1159/000324705)] [Medline: [21430368](https://pubmed.ncbi.nlm.nih.gov/21430368/)]
64. Joly Y, Dalpé G, So D, Birko S. Fair shares and sharing fairly: a survey of public views on open science, informed consent and participatory research in biobanking. *PLoS One* 2015 Jul 8;10(7):e0129893 [FREE Full text] [doi: [10.1371/journal.pone.0129893](https://doi.org/10.1371/journal.pone.0129893)] [Medline: [26154134](https://pubmed.ncbi.nlm.nih.gov/26154134/)]
65. Jones KH, Daniels H, Heys S, Ford DV. Public views on using mobile phone call detail records in health research: qualitative study. *JMIR Mhealth Uhealth* 2019 Jan 16;7(1):e11730 [FREE Full text] [doi: [10.2196/11730](https://doi.org/10.2196/11730)] [Medline: [30664467](https://pubmed.ncbi.nlm.nih.gov/30664467/)]
66. Jones KH, Daniels H, Heys S, Ford DV. Toward an ethically founded framework for the use of mobile phone call detail records in health research. *JMIR Mhealth Uhealth* 2019 Mar 22;7(3):e11969 [FREE Full text] [doi: [10.2196/11969](https://doi.org/10.2196/11969)] [Medline: [30900996](https://pubmed.ncbi.nlm.nih.gov/30900996/)]

67. McCormack P, Kole A, Gainotti S, Mascalcioni D, Molster C, Lochmüller H, et al. 'You should at least ask'. The expectations, hopes and fears of rare disease patients on large-scale data and biomaterial sharing for genomics research. *Eur J Hum Genet* 2016 Oct 6;24(10):1403-1408 [[FREE Full text](#)] [doi: [10.1038/ejhg.2016.30](https://doi.org/10.1038/ejhg.2016.30)] [Medline: [27049302](https://pubmed.ncbi.nlm.nih.gov/27049302/)]
68. Nair K, Willison D, Holbrook A, Keshavjee K. Patients' consent preferences regarding the use of their health information for research purposes: a qualitative study. *J Health Serv Res Policy* 2004 Jan;9(1):22-27. [doi: [10.1258/135581904322716076](https://doi.org/10.1258/135581904322716076)] [Medline: [15006236](https://pubmed.ncbi.nlm.nih.gov/15006236/)]
69. Meulenkamp TM, Gevers SK, Bovenberg JA, Koppelman GH, van Hylckama Vlieg A, Smets EM. Communication of biobanks' research results: what do (potential) participants want? *Am J Med Genet A* 2010 Oct 26;152A(10):2482-2492. [doi: [10.1002/ajmg.a.33617](https://doi.org/10.1002/ajmg.a.33617)] [Medline: [20799322](https://pubmed.ncbi.nlm.nih.gov/20799322/)]
70. Riso B, Tupasela A, Vears DF, Felzmann H, Cockbain J, Loi M, et al. Ethical sharing of health data in online platforms - which values should be considered? *Life Sci Soc Policy* 2017 Aug 21;13(1):12 [[FREE Full text](#)] [doi: [10.1186/s40504-017-0060-z](https://doi.org/10.1186/s40504-017-0060-z)] [Medline: [28825221](https://pubmed.ncbi.nlm.nih.gov/28825221/)]
71. Sanderson SC, Brothers KB, Mercaldo ND, Clayton EW, Antommaria AH, Aufox SA, et al. Public attitudes toward consent and data sharing in biobank research: a large multi-site experimental survey in the US. *Am J Hum Genet* 2017 Mar 02;100(3):414-427 [[FREE Full text](#)] [doi: [10.1016/j.ajhg.2017.01.021](https://doi.org/10.1016/j.ajhg.2017.01.021)] [Medline: [28190457](https://pubmed.ncbi.nlm.nih.gov/28190457/)]
72. Willison DJ, Trowbridge J, Greiver M, Keshavjee K, Mumford D, Sullivan F. Participatory governance over research in an academic research network: the case of diabetes action Canada. *BMJ Open* 2019 Apr 20;9(4):e026828 [[FREE Full text](#)] [doi: [10.1136/bmjopen-2018-026828](https://doi.org/10.1136/bmjopen-2018-026828)] [Medline: [31005936](https://pubmed.ncbi.nlm.nih.gov/31005936/)]
73. Harle C, Golembiewski E, Rahmanian K, Krieger JL, Hagemajer D, Mainous AG, et al. Patient preferences toward an interactive e-consent application for research using electronic health records. *J Am Med Inform Assoc* 2018 Mar 01;25(3):360-368 [[FREE Full text](#)] [doi: [10.1093/jamia/ocx145](https://doi.org/10.1093/jamia/ocx145)] [Medline: [29272408](https://pubmed.ncbi.nlm.nih.gov/29272408/)]
74. Caine K, Kohn S, Lawrence C, Hanania R, Meslin EM, Tierney WM. Designing a patient-centered user interface for access decisions about EHR data: implications from patient interviews. *J Gen Intern Med* 2015 Jan 6;30 Suppl 1(Suppl 1):S7-16 [[FREE Full text](#)] [doi: [10.1007/s11606-014-3049-9](https://doi.org/10.1007/s11606-014-3049-9)] [Medline: [25480719](https://pubmed.ncbi.nlm.nih.gov/25480719/)]
75. Clarke H, Clark S, Birkin M, Iles-Smith H, Glaser A, Morris MA. Understanding barriers to novel data linkages: topic modeling of the results of the LifeInfo survey. *J Med Internet Res* 2021 May 17;23(5):e24236 [[FREE Full text](#)] [doi: [10.2196/24236](https://doi.org/10.2196/24236)] [Medline: [33998998](https://pubmed.ncbi.nlm.nih.gov/33998998/)]
76. Courbier S, Dimond R, Bros-Facer V. Share and protect our health data: an evidence based approach to rare disease patients' perspectives on data sharing and data protection - quantitative survey and recommendations. *Orphanet J Rare Dis* 2019 Jul 12;14(1):175 [[FREE Full text](#)] [doi: [10.1186/s13023-019-1123-4](https://doi.org/10.1186/s13023-019-1123-4)] [Medline: [31300010](https://pubmed.ncbi.nlm.nih.gov/31300010/)]
77. Damschroder LJ, Pritts JL, Neblo MA, Kalarickal RJ, Creswell JW, Hayward RA. Patients, privacy and trust: patients' willingness to allow researchers to access their medical records. *Soc Sci Med* 2007 Jan;64(1):223-235. [doi: [10.1016/j.socscimed.2006.08.045](https://doi.org/10.1016/j.socscimed.2006.08.045)] [Medline: [17045717](https://pubmed.ncbi.nlm.nih.gov/17045717/)]
78. Dirks LG, Shaw JL, Hiratsuka VY, Beans JA, Kelly JJ, Dillard DA. Perspectives on communication and engagement with regard to collecting biospecimens and family health histories for cancer research in a rural Alaska Native community. *J Community Genet* 2019 Jul 30;10(3):435-446 [[FREE Full text](#)] [doi: [10.1007/s12687-019-00408-9](https://doi.org/10.1007/s12687-019-00408-9)] [Medline: [30701443](https://pubmed.ncbi.nlm.nih.gov/30701443/)]
79. Drobotowicz K, Kauppinen M, Kujala S. Trustworthy AI services in the public sector: what are citizens saying about it? In: *Requirements Engineering: Foundation for Software Quality*. Cham: Springer; Apr 2, 2021.
80. Franklin EF, Nichols HM, House L, Buzaglo J, Thiboldeaux K. Cancer patient perspectives on sharing of medical records and mobile device data for research purposes. *J Patient Exp* 2020 Dec 08;7(6):1115-1121 [[FREE Full text](#)] [doi: [10.1177/2374373520923837](https://doi.org/10.1177/2374373520923837)] [Medline: [33457553](https://pubmed.ncbi.nlm.nih.gov/33457553/)]
81. Hammack-Aviran CM, Brelford KM, Beskow LM. Ethical considerations in the conduct of unregulated mHealth research: expert perspectives. *J Law Med Ethics* 2020 Mar 01;48(1_suppl):9-36 [[FREE Full text](#)] [doi: [10.1177/1073110520917027](https://doi.org/10.1177/1073110520917027)] [Medline: [32342756](https://pubmed.ncbi.nlm.nih.gov/32342756/)]
82. Hassan L, Dalton A, Hammond C, Tully MP. A deliberative study of public attitudes towards sharing genomic data within NHS genomic medicine services in England. *Public Underst Sci* 2020 Oct 15;29(7):702-717 [[FREE Full text](#)] [doi: [10.1177/0963662520942132](https://doi.org/10.1177/0963662520942132)] [Medline: [32664786](https://pubmed.ncbi.nlm.nih.gov/32664786/)]
83. Hobbs A, Starkbaum J, Gottweis U, Wichmann H, Gottweis H. The privacy-reciprocity connection in biobanking: comparing German with UK strategies. *Public Health Genomics* 2012 Jun 20;15(5):272-284 [[FREE Full text](#)] [doi: [10.1159/000336671](https://doi.org/10.1159/000336671)] [Medline: [22722691](https://pubmed.ncbi.nlm.nih.gov/22722691/)]
84. Kim J, Kim H, Bell E, Bath T, Paul P, Pham A, et al. Patient perspectives about decisions to share medical data and biospecimens for research. *JAMA Netw Open* 2019 Aug 02;2(8):e199550 [[FREE Full text](#)] [doi: [10.1001/jamanetworkopen.2019.9550](https://doi.org/10.1001/jamanetworkopen.2019.9550)] [Medline: [31433479](https://pubmed.ncbi.nlm.nih.gov/31433479/)]
85. Milne R, Morley KI, Almarri MA, Anwer S, Atutornu J, Baranova EE, et al. Demonstrating trustworthiness when collecting and sharing genomic data: public views across 22 countries. *Genome Med* 2021 May 25;13(1):92 [[FREE Full text](#)] [doi: [10.1186/s13073-021-00903-0](https://doi.org/10.1186/s13073-021-00903-0)] [Medline: [34034801](https://pubmed.ncbi.nlm.nih.gov/34034801/)]
86. Mursaleen LR, Stamford JA, Jones DA, Windle R, Isaacs T. Attitudes towards data collection, ownership and sharing among patients with parkinson's disease. *J Parkinsons Dis* 2017 Aug 08;7(3):523-531. [doi: [10.3233/jpd-161045](https://doi.org/10.3233/jpd-161045)]

87. Paprica PA, Sutherland E, Smith A, Brudno M, Cartagena RG, Crichlow M, et al. Essential requirements for establishing and operating data trusts: practical guidance co-developed by representatives from fifteen canadian organizations and initiatives. *Int J Popul Data Sci* 2020 Aug 24;5(1):1353 [FREE Full text] [doi: [10.23889/ijpds.v5i1.1353](https://doi.org/10.23889/ijpds.v5i1.1353)] [Medline: [33644412](https://pubmed.ncbi.nlm.nih.gov/33644412/)]
88. Platt J, Bollinger J, Dvoskin R, Kardias SL, Kaufman D. Public preferences regarding informed consent models for participation in population-based genomic research. *Genet Med* 2014 Jan;16(1):11-18 [FREE Full text] [doi: [10.1038/gim.2013.59](https://doi.org/10.1038/gim.2013.59)] [Medline: [23660530](https://pubmed.ncbi.nlm.nih.gov/23660530/)]
89. Tauali i M, Davis EL, Braun KL, Tsark JU, Brown N, Hudson M, et al. Native Hawaiian views on biobanking. *J Cancer Educ* 2014 Sep 29;29(3):570-576 [FREE Full text] [doi: [10.1007/s13187-014-0638-6](https://doi.org/10.1007/s13187-014-0638-6)] [Medline: [24683042](https://pubmed.ncbi.nlm.nih.gov/24683042/)]
90. Teng J, Bentley C, Burgess MM, O'Doherty KC, McGrail KM. Sharing linked data sets for research: results from a deliberative public engagement event in British Columbia, Canada. *Int J Popul Data Sci* 2019 May 07;4(1):1103 [FREE Full text] [doi: [10.23889/ijpds.v4i1.1103](https://doi.org/10.23889/ijpds.v4i1.1103)] [Medline: [34095532](https://pubmed.ncbi.nlm.nih.gov/34095532/)]
91. Trinidad SB, Fullerton SM, Bares JM, Jarvik GP, Larson EB, Burke W. Informed consent in genome-scale research: what do prospective participants think? *AJOB Prim Res* 2012 Jul 01;3(3):3-11 [FREE Full text] [doi: [10.1080/21507716.2012.662575](https://doi.org/10.1080/21507716.2012.662575)] [Medline: [23493836](https://pubmed.ncbi.nlm.nih.gov/23493836/)]
92. Woodbury RB, Beans JA, Wark KA, Spicer P, Hiratsuka VY. Community perspectives on communicating about precision medicine in an alaska native tribal health care system. *Front Commun (Lausanne)* 2020 Sep 25;5:70 [FREE Full text] [doi: [10.3389/fcomm.2020.00070](https://doi.org/10.3389/fcomm.2020.00070)] [Medline: [33511166](https://pubmed.ncbi.nlm.nih.gov/33511166/)]
93. NICE Citizens Council. What Ethical and Practical Issues Need to Be Considered in the Use of Anonymised Information Derived from Personal Care Records as Part of the Evaluation of Treatments and Delivery of Care? [Internet]. London, United Kingdom: National Institute for Health and Care Excellence (NICE); 2015.
94. Lysaght T, Ballantyne A, Xafis V, Ong S, Schaefer GO, Ling JM, et al. "Who is watching the watchdog?": ethical perspectives of sharing health-related data for precision medicine in Singapore. *BMC Med Ethics* 2020 Nov 19;21(1):118 [FREE Full text] [doi: [10.1186/s12910-020-00561-8](https://doi.org/10.1186/s12910-020-00561-8)] [Medline: [33213433](https://pubmed.ncbi.nlm.nih.gov/33213433/)]
95. Willison D, Keshavjee K, Nair K, Goldsmith C, Holbrook A, Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness investigators. Patients' consent preferences for research uses of information in electronic medical records: interview and survey data. *BMJ* 2003 Feb 15;326(7385):373 [FREE Full text] [doi: [10.1136/bmj.326.7385.373](https://doi.org/10.1136/bmj.326.7385.373)] [Medline: [12586673](https://pubmed.ncbi.nlm.nih.gov/12586673/)]
96. Liyanage H, Liaw S, Di Iorio CT, Kuziemy C, Schreiber R, Terry AL, et al. Building a privacy, ethics, and data access framework for real world computerised medical record system data: a delphi study. *Yearb Med Inform* 2018 Mar 06;25(01):138-145. [doi: [10.15265/iy-2016-035](https://doi.org/10.15265/iy-2016-035)]
97. Street J, Fabianesi B, Adams C, Flack F, Smith M, Carter SM, et al. Sharing administrative health data with private industry: a report on two citizens' juries. *Health Expect* 2021 Aug;24(4):1337-1348 [FREE Full text] [doi: [10.1111/hex.13268](https://doi.org/10.1111/hex.13268)] [Medline: [34048624](https://pubmed.ncbi.nlm.nih.gov/34048624/)]
98. Barazzetti G, Bosisio F, Koutaissoff D, Spencer B. Broad consent in practice: lessons learned from a hospital-based biobank for prospective research on genomic and medical data. *Eur J Hum Genet* 2020 Jul 21;28(7):915-924 [FREE Full text] [doi: [10.1038/s41431-020-0585-0](https://doi.org/10.1038/s41431-020-0585-0)] [Medline: [32086443](https://pubmed.ncbi.nlm.nih.gov/32086443/)]
99. Rivas Velarde MC, Tsantoulis P, Burton-Jeangros C, Aceti M, Chappuis P, Hurst-Majno S. Citizens' views on sharing their health data: the role of competence, reliability and pursuing the common good. *BMC Med Ethics* 2021 May 18;22(1):62 [FREE Full text] [doi: [10.1186/s12910-021-00633-3](https://doi.org/10.1186/s12910-021-00633-3)] [Medline: [34006284](https://pubmed.ncbi.nlm.nih.gov/34006284/)]
100. Tracy CS, Dantas GC, Upshur RE. Feasibility of a patient decision aid regarding disclosure of personal health information: qualitative evaluation of the Health Care Information Directive. *BMC Med Inform Decis Mak* 2004 Sep 10;4(1):13 [FREE Full text] [doi: [10.1186/1472-6947-4-13](https://doi.org/10.1186/1472-6947-4-13)] [Medline: [15361257](https://pubmed.ncbi.nlm.nih.gov/15361257/)]
101. Sabatello M, Blake LA, Chao A, Silverman A, Ovadia Mazzoni R, Zhang Y, et al. Including the blind community in precision medicine research: findings from a national survey and recommendations. *Genet Med* 2019 Nov;21(11):2631-2638 [FREE Full text] [doi: [10.1038/s41436-019-0533-y](https://doi.org/10.1038/s41436-019-0533-y)] [Medline: [31092907](https://pubmed.ncbi.nlm.nih.gov/31092907/)]
102. Peppercorn J, Campbell E, Isakoff S, Horick NK, Rabin J, Quain K, et al. Patient preferences for use of archived biospecimens from oncology trials when adequacy of informed consent is unclear. *Oncologist* 2020 Jan;25(1):78-86 [FREE Full text] [doi: [10.1634/theoncologist.2019-0365](https://doi.org/10.1634/theoncologist.2019-0365)] [Medline: [31492767](https://pubmed.ncbi.nlm.nih.gov/31492767/)]
103. Schmit C, Ajayi KV, Ferdinand AO, Giannouchos T, Ilangovan G, Nowell WB, et al. Communicating with patients about software for enhancing privacy in secondary database research involving record linkage: delphi study. *J Med Internet Res* 2020 Dec 15;22(12):e20783 [FREE Full text] [doi: [10.2196/20783](https://doi.org/10.2196/20783)] [Medline: [33320097](https://pubmed.ncbi.nlm.nih.gov/33320097/)]
104. Tully MP, Hassan L, Oswald M, Ainsworth J. Commercial use of health data-A public "trial" by citizens' jury. *Learn Health Syst* 2019 Oct 18;3(4):e10200 [FREE Full text] [doi: [10.1002/lrh2.10200](https://doi.org/10.1002/lrh2.10200)] [Medline: [31641688](https://pubmed.ncbi.nlm.nih.gov/31641688/)]
105. Davidson S, Mclean C, Treanor S, Aitken M, Cunningham-Burley S, Laurie G, et al. Public acceptability of data sharing between the public, private and third sectors for research purposes. Scottish Government. 2013. URL: <https://www.research.ed.ac.uk/en/publications/public-acceptability-of-data-sharing-between-the-public-private-a> [accessed 2022-09-27]

106. Mazor KM, Richards A, Gallagher M, Arterburn DE, Raebel MA, Nowell WB, et al. Stakeholders' views on data sharing in multicenter studies. *J Comp Eff Res* 2017 Sep;6(6):537-547 [[FREE Full text](#)] [doi: [10.2217/cer-2017-0009](https://doi.org/10.2217/cer-2017-0009)] [Medline: [28805448](https://pubmed.ncbi.nlm.nih.gov/28805448/)]
107. Cobban S, Edgington E, Pimlott J. An ethical perspective on research using shared data. *Can J Dental Hygiene* 2008;42(5):233-238 [[FREE Full text](#)]
108. McCradden MD, Baba A, Saha A, Ahmad S, Boparai K, Fadaiefard P, et al. Ethical concerns around use of artificial intelligence in health care research from the perspective of patients with meningioma, caregivers and health care providers: a qualitative study. *CMAJ Open* 2020 Feb 18;8(1):E90-E95 [[FREE Full text](#)] [doi: [10.9778/cmajo.20190151](https://doi.org/10.9778/cmajo.20190151)] [Medline: [32071143](https://pubmed.ncbi.nlm.nih.gov/32071143/)]
109. Kim KK, Browe DK, Logan HC, Holm R, Hack L, Ohno-Machado L. Data governance requirements for distributed clinical research networks: triangulating perspectives of diverse stakeholders. *J Am Med Inform Assoc* 2014;21(4):714-719 [[FREE Full text](#)] [doi: [10.1136/amiajnl-2013-002308](https://doi.org/10.1136/amiajnl-2013-002308)] [Medline: [24302285](https://pubmed.ncbi.nlm.nih.gov/24302285/)]
110. De Vries RG, Ryan KA, Gordon L, Krenz CD, Tomlinson T, Jewell S, et al. Biobanks and the moral concerns of donors: a democratic deliberation. *Qual Health Res* 2019 Nov 10;29(13):1942-1953. [doi: [10.1177/1049732318791826](https://doi.org/10.1177/1049732318791826)] [Medline: [30095038](https://pubmed.ncbi.nlm.nih.gov/30095038/)]
111. Kasperbauer TJ. Protecting health privacy even when privacy is lost. *J Med Ethics* 2020 Nov 05;46(11):768-772. [doi: [10.1136/medethics-2019-105880](https://doi.org/10.1136/medethics-2019-105880)] [Medline: [31806677](https://pubmed.ncbi.nlm.nih.gov/31806677/)]
112. The One-Way Mirror: public attitudes to commercial access to health data Report prepared for the Wellcome Trust. Ipsos MORI. 2016 Mar. URL: <https://www.ipsos.com/sites/default/files/publication/5200-03/sri-wellcome-trust-commercial-access-to-health-data.pdf> [accessed 2022-03-02]
113. Middleton A, Milne R, Thorogood A, Kleiderman E, Niemiec E, Prainsack B, et al. Attitudes of publics who are unwilling to donate DNA data for research. *Eur J Med Genet* 2019 May;62(5):316-323 [[FREE Full text](#)] [doi: [10.1016/j.ejmg.2018.11.014](https://doi.org/10.1016/j.ejmg.2018.11.014)] [Medline: [30476628](https://pubmed.ncbi.nlm.nih.gov/30476628/)]
114. Raj M, Ryan K, Nong P, Calhoun K, Trinidad MG, De Vries R, et al. Public deliberation process on patient perspectives on health information sharing: evaluative descriptive study. *JMIR Cancer* 2022 Sep 16;8(3):e37793 [[FREE Full text](#)] [doi: [10.2196/37793](https://doi.org/10.2196/37793)] [Medline: [36112409](https://pubmed.ncbi.nlm.nih.gov/36112409/)]
115. McCormick JB, Hopkins M, Lehman EB, Green MJ. Mining the data: exploring rural patients' attitudes about the use of their personal information in research. *AJOB Empir Bioeth* 2022 Mar 10;13(2):89-106. [doi: [10.1080/23294515.2022.2040644](https://doi.org/10.1080/23294515.2022.2040644)] [Medline: [35271430](https://pubmed.ncbi.nlm.nih.gov/35271430/)]
116. McCormick J, Hopkins M. Exploring public concerns for sharing and governance of personal health information: a focus group study. *JAMIA Open* 2021 Oct;4(4):ooab098 [[FREE Full text](#)] [doi: [10.1093/jamiaopen/ooab098](https://doi.org/10.1093/jamiaopen/ooab098)] [Medline: [34926998](https://pubmed.ncbi.nlm.nih.gov/34926998/)]
117. Richter G, Borzikowsky C, Lieb W, Schreiber S, Krawczak M, Buyx A. Patient views on research use of clinical data without consent: legal, but also acceptable? *Eur J Hum Genet* 2019 Jun 25;27(6):841-847 [[FREE Full text](#)] [doi: [10.1038/s41431-019-0340-6](https://doi.org/10.1038/s41431-019-0340-6)] [Medline: [30683927](https://pubmed.ncbi.nlm.nih.gov/30683927/)]
118. Geneviève LD, Martani A, Elger BS, Wangmo T. Individual notions of fair data sharing from the perspectives of Swiss stakeholders. *BMC Health Serv Res* 2021 Sep 23;21(1):1007 [[FREE Full text](#)] [doi: [10.1186/s12913-021-06906-2](https://doi.org/10.1186/s12913-021-06906-2)] [Medline: [34551742](https://pubmed.ncbi.nlm.nih.gov/34551742/)]
119. Kaufman DJ, Murphy-Bollinger J, Scott J, Hudson KL. Public opinion about the importance of privacy in biobank research. *Am J Hum Genet* 2009 Nov;85(5):643-654 [[FREE Full text](#)] [doi: [10.1016/j.ajhg.2009.10.002](https://doi.org/10.1016/j.ajhg.2009.10.002)] [Medline: [19878915](https://pubmed.ncbi.nlm.nih.gov/19878915/)]
120. Mouton Dorey C, Baumann H, Biller-Andorno N. Patient data and patient rights: Swiss healthcare stakeholders' ethical awareness regarding large patient data sets - a qualitative study. *BMC Med Ethics* 2018 Mar 07;19(1):20 [[FREE Full text](#)] [doi: [10.1186/s12910-018-0261-x](https://doi.org/10.1186/s12910-018-0261-x)] [Medline: [29514635](https://pubmed.ncbi.nlm.nih.gov/29514635/)]
121. Snell K, Starkbaum J, Lauß G, Vermeer A, Helén I. From protection of privacy to control of data streams: a focus group study on biobanks in the information society. *Public Health Genomics* 2012 Jun 20;15(5):293-302. [doi: [10.1159/000336541](https://doi.org/10.1159/000336541)] [Medline: [22722693](https://pubmed.ncbi.nlm.nih.gov/22722693/)]
122. Dimitropoulos L, Patel V, Scheffler S, Posnack S. Public attitudes toward health information exchange: perceived benefits and concerns. *Am J Manag Care* 2011 Dec;17(12 Spec No):SP111-SP116 [[FREE Full text](#)] [Medline: [22216769](https://pubmed.ncbi.nlm.nih.gov/22216769/)]
123. Mayo RM, Summey JF, Williams JE, Spence RA, Kim S, Jagsi R. Qualitative study of oncologists' views on the CancerLinQ rapid learning system. *J Oncol Pract* 2017 Mar;13(3):e176-e184. [doi: [10.1200/jop.2016.016816](https://doi.org/10.1200/jop.2016.016816)]
124. Middleton A, Milne R, Howard H, Niemiec E, Robarts L, Critchley C, Participant Values Work Stream of the Global Alliance for GenomicsHealth. Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data. *Eur J Hum Genet* 2020 Apr 29;28(4):424-434 [[FREE Full text](#)] [doi: [10.1038/s41431-019-0550-y](https://doi.org/10.1038/s41431-019-0550-y)] [Medline: [31784701](https://pubmed.ncbi.nlm.nih.gov/31784701/)]
125. Annas GJ. HIPAA regulations - a new era of medical-record privacy? *N Engl J Med* 2003 Apr 10;348(15):1486-1490. [doi: [10.1056/NEJLim035027](https://doi.org/10.1056/NEJLim035027)] [Medline: [12686707](https://pubmed.ncbi.nlm.nih.gov/12686707/)]
126. Maiorana A, Steward WT, Koester KA, Pearson C, Shade SB, Chakravarty D, et al. Trust, confidentiality, and the acceptability of sharing HIV-related patient data: lessons learned from a mixed methods study about Health Information Exchanges. *Implement Sci* 2012 Apr 19;7(1):34 [[FREE Full text](#)] [doi: [10.1186/1748-5908-7-34](https://doi.org/10.1186/1748-5908-7-34)] [Medline: [22515736](https://pubmed.ncbi.nlm.nih.gov/22515736/)]

127. McGuire AL, Achenbaum LS, Whitney SN, Slashinski MJ, Versalovic J, Keitel WA, et al. Perspectives on human microbiome research ethics. *J Empir Res Hum Res Ethics* 2012 Jul 01;7(3):1-14 [[FREE Full text](#)] [doi: [10.1525/jer.2012.7.3.1](https://doi.org/10.1525/jer.2012.7.3.1)] [Medline: [22850139](https://pubmed.ncbi.nlm.nih.gov/22850139/)]
128. Colombo C, Roberto A, Krljeza-Jeric K, Parmelli E, Banzi R. Sharing individual participant data from clinical studies: a cross-sectional online survey among Italian patient and citizen groups. *BMJ Open* 2019 Feb 19;9(2):e024863 [[FREE Full text](#)] [doi: [10.1136/bmjopen-2018-024863](https://doi.org/10.1136/bmjopen-2018-024863)] [Medline: [30782920](https://pubmed.ncbi.nlm.nih.gov/30782920/)]
129. Chung A, Vu M, Myers K, Burris J, Kappelman M. Crohn's and colitis foundation of America partners patient-powered research network: patient perspectives on facilitators and barriers to building an impactful patient-powered research network. *Med Care* 2018 Oct;56 Suppl 10 Suppl 1(10 Suppl 1):S33-S40 [[FREE Full text](#)] [doi: [10.1097/MLR.0000000000000771](https://doi.org/10.1097/MLR.0000000000000771)] [Medline: [30074949](https://pubmed.ncbi.nlm.nih.gov/30074949/)]
130. Dove E, Phillips M. Privacy law, data sharing policies, and medical data: a comparative perspective. In: *Medical Data Privacy Handbook*. Cham: Springer; 2015.
131. Mbuthia D, Molyneux S, Njue M, Mwalukore S, Marsh V. Kenyan health stakeholder views on individual consent, general notification and governance processes for the re-use of hospital inpatient data to support learning on healthcare systems. *BMC Med Ethics* 2019 Jan 08;20(1):3 [[FREE Full text](#)] [doi: [10.1186/s12910-018-0343-9](https://doi.org/10.1186/s12910-018-0343-9)] [Medline: [30621693](https://pubmed.ncbi.nlm.nih.gov/30621693/)]
132. Douglas A, Ward H, Bhopal R, Kirkpatrick T, Sayed-Rafiq A, Gruer L, SHELS researchers. Is the linkage of census and health data justified? Views from a public panel of the Scottish Health and Ethnicity Linkage study. *J Public Health (Oxf)* 2018 Jun 01;40(2):435-440. [doi: [10.1093/pubmed/fox060](https://doi.org/10.1093/pubmed/fox060)] [Medline: [28541459](https://pubmed.ncbi.nlm.nih.gov/28541459/)]
133. Alaqra AS, Kane B, Fischer-Hübner S. Machine learning-based analysis of encrypted medical data in the cloud: qualitative study of expert stakeholders' perspectives. *JMIR Hum Factors* 2021 Sep 16;8(3):e21810 [[FREE Full text](#)] [doi: [10.2196/21810](https://doi.org/10.2196/21810)] [Medline: [34528892](https://pubmed.ncbi.nlm.nih.gov/34528892/)]
134. Vezyridis P, Timmons S. Resisting big data exploitations in public healthcare: free riding or distributive justice? *Sociol Health Illn* 2019 Nov 18;41(8):1585-1599. [doi: [10.1111/1467-9566.12969](https://doi.org/10.1111/1467-9566.12969)] [Medline: [31423602](https://pubmed.ncbi.nlm.nih.gov/31423602/)]
135. Muller SH, van Thiel GJ, Vrana M, Mostert M, van Delden JJ. Patients' and publics' preferences for data-intensive health research governance: survey study. *JMIR Hum Factors* 2022 Sep 07;9(3):e36797 [[FREE Full text](#)] [doi: [10.2196/36797](https://doi.org/10.2196/36797)] [Medline: [36069794](https://pubmed.ncbi.nlm.nih.gov/36069794/)]
136. Shah N, Viberg Johansson J, Haraldsdóttir E, Bentzen H, Coy S, Mascalonzi D, et al. Governing health data across changing contexts: a focus group study of citizen's views in England, Iceland, and Sweden. *Int J Med Inform* 2021 Dec;156:104623. [doi: [10.1016/j.ijmedinf.2021.104623](https://doi.org/10.1016/j.ijmedinf.2021.104623)] [Medline: [34717179](https://pubmed.ncbi.nlm.nih.gov/34717179/)]
137. Ormondroyd E, Border P, Hayward J, Papanikitas A. Genomic health data generation in the UK: a 360 view. *Eur J Hum Genet* 2022 Jul 19;30(7):782-789 [[FREE Full text](#)] [doi: [10.1038/s41431-021-00976-w](https://doi.org/10.1038/s41431-021-00976-w)] [Medline: [34663916](https://pubmed.ncbi.nlm.nih.gov/34663916/)]
138. Manhas KP, Page S, Dodd SX, Letourneau N, Ambrose A, Cui X, et al. Parent perspectives on privacy and governance for a pediatric repository of non-biological, research data. *J Empir Res Hum Res Ethics* 2015 Feb 31;10(1):88-99. [doi: [10.1177/1556264614564970](https://doi.org/10.1177/1556264614564970)] [Medline: [25742670](https://pubmed.ncbi.nlm.nih.gov/25742670/)]
139. McCradden MD, Sarker T, Paprica PA. Conditionally positive: a qualitative study of public perceptions about using health data for artificial intelligence research. *BMJ Open* 2020 Oct 28;10(10):e039798 [[FREE Full text](#)] [doi: [10.1136/bmjopen-2020-039798](https://doi.org/10.1136/bmjopen-2020-039798)] [Medline: [33115901](https://pubmed.ncbi.nlm.nih.gov/33115901/)]
140. Bromley E, Mendoza-Graf A, Berry S, Nebeker C, Khodyakov D. From "informed" to "engaged" consent: risks and obligations in consent for participation in a health data repository. *J Law Med Ethics* 2020 Mar 01;48(1):172-182. [doi: [10.1177/1073110520917007](https://doi.org/10.1177/1073110520917007)] [Medline: [32342789](https://pubmed.ncbi.nlm.nih.gov/32342789/)]
141. Tsai F, Junod V. Medical research using governments' health claims databases: with or without patients' consent? *J Public Health (Oxf)* 2018 Dec 01;40(4):871-877. [doi: [10.1093/pubmed/fox034](https://doi.org/10.1093/pubmed/fox034)] [Medline: [29506041](https://pubmed.ncbi.nlm.nih.gov/29506041/)]
142. Page SA, Manhas KP, Muruve DA. A survey of patient perspectives on the research use of health information and biospecimens. *BMC Med Ethics* 2016 Aug 15;17(1):48 [[FREE Full text](#)] [doi: [10.1186/s12910-016-0130-4](https://doi.org/10.1186/s12910-016-0130-4)] [Medline: [27527514](https://pubmed.ncbi.nlm.nih.gov/27527514/)]
143. Spencer K, Sanders C, Whitley EA, Lund D, Kaye J, Dixon WG. Patient perspectives on sharing anonymized personal health data using a digital system for dynamic consent and research feedback: a qualitative study. *J Med Internet Res* 2016 Apr 15;18(4):e66 [[FREE Full text](#)] [doi: [10.2196/jmir.5011](https://doi.org/10.2196/jmir.5011)] [Medline: [27083521](https://pubmed.ncbi.nlm.nih.gov/27083521/)]
144. Hiratsuka V, Brown JK, Hoeft TJ, Dillard DA. Alaska native people's perceptions, understandings, and expectations for research involving biological specimens. *Int J Circumpolar Health* 2012 May 22;71(1):18642 [[FREE Full text](#)] [doi: [10.3402/ijch.v71i10.18642](https://doi.org/10.3402/ijch.v71i10.18642)] [Medline: [22663942](https://pubmed.ncbi.nlm.nih.gov/22663942/)]
145. Bull S, Cheah PY, Denny S, Jao I, Marsh V, Merson L, et al. Best practices for ethical sharing of individual-level health research data from low- and middle-income settings. *J Empir Res Hum Res Ethics* 2015 Jul 21;10(3):302-313 [[FREE Full text](#)] [doi: [10.1177/1556264615594606](https://doi.org/10.1177/1556264615594606)] [Medline: [26297751](https://pubmed.ncbi.nlm.nih.gov/26297751/)]
146. Kaphingst K, Janoff J, Harris L, Emmons K. Views of female breast cancer patients who donated biologic samples regarding storage and use of samples for genetic research. *Clin Genet* 2006 May;69(5):393-398. [doi: [10.1111/j.1399-0004.2006.00614.x](https://doi.org/10.1111/j.1399-0004.2006.00614.x)] [Medline: [16650074](https://pubmed.ncbi.nlm.nih.gov/16650074/)]

147. Brall C, Berlin C, Zwahlen M, Ormond KE, Egger M, Vayena E. Public willingness to participate in personalized health research and biobanking: a large-scale Swiss survey. *PLoS One* 2021 Apr 1;16(4):e0249141 [[FREE Full text](#)] [doi: [10.1371/journal.pone.0249141](https://doi.org/10.1371/journal.pone.0249141)] [Medline: [33793624](#)]
148. Kaufman D, Murphy J, Erby L, Hudson K, Scott J. Veterans' attitudes regarding a database for genomic research. *Genetics Med* 2009 May;11(5):329-337. [doi: [10.1097/gim.0b013e31819994f8](https://doi.org/10.1097/gim.0b013e31819994f8)]
149. Kerath SM, Klein G, Kern M, Shapira I, Witthuhn J, Norohna N, et al. Beliefs and attitudes towards participating in genetic research - a population based cross-sectional study. *BMC Public Health* 2013 Feb 07;13(1):114 [[FREE Full text](#)] [doi: [10.1186/1471-2458-13-114](https://doi.org/10.1186/1471-2458-13-114)] [Medline: [23388465](#)]
150. Master Z, Claudio JO, Rachul C, Wang JC, Minden MD, Caulfield T. Cancer patient perceptions on the ethical and legal issues related to biobanking. *BMC Med Genomics* 2013 Mar 08;6(1):8 [[FREE Full text](#)] [doi: [10.1186/1755-8794-6-8](https://doi.org/10.1186/1755-8794-6-8)] [Medline: [23497701](#)]
151. Ruiz-Canela M, Valle-Mansilla JI, Sulmasy DP. What research participants want to know about genetic research results: the impact of "genetic exceptionalism". *J Empir Res Hum Res Ethics* 2011 Sep 01;6(3):39-46. [doi: [10.1525/jer.2011.6.3.39](https://doi.org/10.1525/jer.2011.6.3.39)] [Medline: [21931236](#)]
152. Tabor HK, Stock J, Brazg T, McMillin MJ, Dent KM, Yu J, et al. Informed consent for whole genome sequencing: a qualitative analysis of participant expectations and perceptions of risks, benefits, and harms. *Am J Med Genet A* 2012 Jun 24;158A(6):1310-1319 [[FREE Full text](#)] [doi: [10.1002/ajmg.a.35328](https://doi.org/10.1002/ajmg.a.35328)] [Medline: [22532433](#)]
153. Seltzer E, Goldshear J, Guntuku SC, Grande D, Asch DA, Klinger EV, et al. Patients' willingness to share digital health and non-health data for research: a cross-sectional study. *BMC Med Inform Decis Mak* 2019 Aug 08;19(1):157 [[FREE Full text](#)] [doi: [10.1186/s12911-019-0886-9](https://doi.org/10.1186/s12911-019-0886-9)] [Medline: [31395102](#)]
154. Eikemo H, Roten LT, Vaaler AE. Research based on existing clinical data and biospecimens: a systematic study of patients' opinions. *BMC Med Ethics* 2022 Jun 16;23(1):60 [[FREE Full text](#)] [doi: [10.1186/s12910-022-00799-4](https://doi.org/10.1186/s12910-022-00799-4)] [Medline: [35710552](#)]
155. Burstein M, Robinson J, Hilsenbeck S, McGuire A, Lau C. Pediatric data sharing in genomic research: attitudes and preferences of parents. *Pediatrics* 2014 Apr;133(4):690-697 [[FREE Full text](#)] [doi: [10.1542/peds.2013-1592](https://doi.org/10.1542/peds.2013-1592)] [Medline: [24616359](#)]
156. Meulenkamp TM, Gevers SJ, Bovenberg JA, Smets EM. Researchers' opinions towards the communication of results of biobank research: a survey study. *Eur J Hum Genet* 2012 Mar 30;20(3):258-262 [[FREE Full text](#)] [doi: [10.1038/ejhg.2011.216](https://doi.org/10.1038/ejhg.2011.216)] [Medline: [22126749](#)]
157. Richards JE, Bane E, Fullerton SM, Ludman EJ, Jarvik G. Allocation of resources to communication of research result summaries. *J Empir Res Hum Res Ethics* 2016 Oct 19;11(4):364-369 [[FREE Full text](#)] [doi: [10.1177/1556264616667126](https://doi.org/10.1177/1556264616667126)] [Medline: [27613778](#)]
158. Tosoni S, Voruganti I, Lajkosz K, Habal F, Murphy P, Wong RK, et al. The use of personal health information outside the circle of care: consent preferences of patients from an academic health care institution. *BMC Med Ethics* 2021 Mar 24;22(1):29 [[FREE Full text](#)] [doi: [10.1186/s12910-021-00598-3](https://doi.org/10.1186/s12910-021-00598-3)] [Medline: [33761938](#)]
159. Rushmer R, Themessel-Huber M, Coyle J, Humphris G, Dowell J, Williams B. Is the routine recording of primary care consultations possible ... and desirable? Lessons for researchers from a consultation with multiple stakeholders. *Patient Educ Couns* 2011 Feb;82(2):247-253. [doi: [10.1016/j.pec.2010.04.020](https://doi.org/10.1016/j.pec.2010.04.020)] [Medline: [20547028](#)]
160. Köngeter A, Schickhardt C, Jungkunz M, Bergbold S, Mehliis K, Winkler EC. Patients' willingness to provide their clinical data for research purposes and acceptance of different consent models: findings from a representative survey of patients with cancer. *J Med Internet Res* 2022 Aug 25;24(8):e37665 [[FREE Full text](#)] [doi: [10.2196/37665](https://doi.org/10.2196/37665)] [Medline: [36006690](#)]
161. Clerkin P, Buckley BS, Murphy AW, MacFarlane AE. Patients' views about the use of their personal information from general practice medical records in health research: a qualitative study in Ireland. *Fam Pract* 2013 Feb;30(1):105-112. [doi: [10.1093/fampra/cms036](https://doi.org/10.1093/fampra/cms036)] [Medline: [22850249](#)]
162. Tully MP, Bozentko K, Clement S, Hunn A, Hassan L, Norris R, et al. Investigating the extent to which patients should control access to patient records for research: a deliberative process using citizens' juries. *J Med Internet Res* 2018 Mar 28;20(3):e112 [[FREE Full text](#)] [doi: [10.2196/jmir.7763](https://doi.org/10.2196/jmir.7763)] [Medline: [29592847](#)]
163. Xafis V. The acceptability of conducting data linkage research without obtaining consent: lay people's views and justifications. *BMC Med Ethics* 2015 Nov 17;16(1):79 [[FREE Full text](#)] [doi: [10.1186/s12910-015-0070-4](https://doi.org/10.1186/s12910-015-0070-4)] [Medline: [26577591](#)]
164. Hate K, Meherally S, Shah More N, Jayaraman A, Bull S, Parker M, et al. Sweat, skepticism, and uncharted territory: a qualitative study of opinions on data sharing among public health researchers and research participants in Mumbai, India. *J Empir Res Hum Res Ethics* 2015 Jul 21;10(3):239-250 [[FREE Full text](#)] [doi: [10.1177/1556264615592383](https://doi.org/10.1177/1556264615592383)] [Medline: [26297746](#)]
165. McGuire AL, Hamilton JA, Lunstroth R, McCullough LB, Goldman A. DNA data sharing: research participants' perspectives. *Genetics Med* 2008 Jan;10(1):46-53. [doi: [10.1097/gim.0b013e31815f1e00](https://doi.org/10.1097/gim.0b013e31815f1e00)]
166. Thabrew H, Aljawahiri N, Kumar H, Bowden N, Milne B, Pricor M, et al. 'As long as it's used for beneficial things': an investigation of non-Māori, Māori and young people's perceptions regarding the research use of the Aotearoa New Zealand integrated data infrastructure (IDI). *J Empir Res Hum Res Ethics* 2022 Oct 18;17(4):471-482. [doi: [10.1177/15562646221111294](https://doi.org/10.1177/15562646221111294)] [Medline: [35849389](#)]

167. Cheung C, Bietz MJ, Patrick K, Bloss CS. Privacy attitudes among early adopters of emerging health technologies. *PLoS One* 2016 Nov 10;11(11):e0166389 [FREE Full text] [doi: [10.1371/journal.pone.0166389](https://doi.org/10.1371/journal.pone.0166389)] [Medline: [27832194](https://pubmed.ncbi.nlm.nih.gov/27832194/)]
168. Monaghan T, Manski-Nankervis J, Canaway R. Big data or big risk: general practitioner, practice nurse and practice manager attitudes to providing de-identified patient health data from electronic medical records to researchers. *Aust J Prim Health* 2020;26(6):466. [doi: [10.1071/py20153](https://doi.org/10.1071/py20153)]
169. Mulrine S, Blell M, Murtagh M. Beyond trust: amplifying unheard voices on concerns about harm resulting from health data-sharing. *Med Access Point Care* 2021 Oct 01;5:23992026211048421 [FREE Full text] [doi: [10.1177/23992026211048421](https://doi.org/10.1177/23992026211048421)] [Medline: [36204496](https://pubmed.ncbi.nlm.nih.gov/36204496/)]
170. Edwards K, Lemke A, Trinidad S, Lewis S, Starks H, Quinn Griffin M, et al. Attitudes toward genetic research review: results from a survey of human genetics researchers. *Public Health Genomics* 2011 Apr 11;14(6):337-345 [FREE Full text] [doi: [10.1159/000324931](https://doi.org/10.1159/000324931)] [Medline: [21487211](https://pubmed.ncbi.nlm.nih.gov/21487211/)]
171. Manhas KP, Dodd SX, Page S, Letourneau N, Adair CE, Cui X, et al. Sharing longitudinal, non-biological birth cohort data: a cross-sectional analysis of parent consent preferences. *BMC Med Inform Decis Mak* 2018 Nov 12;18(1):97 [FREE Full text] [doi: [10.1186/s12911-018-0683-x](https://doi.org/10.1186/s12911-018-0683-x)] [Medline: [30419910](https://pubmed.ncbi.nlm.nih.gov/30419910/)]
172. Hivon J, Titah R. Conceptualizing citizen participation in open data use at the city level. *Transform Gov People Process Policy* 2017 Mar 20;11(1):99-118. [doi: [10.1108/tg-12-2015-0053](https://doi.org/10.1108/tg-12-2015-0053)]
173. Jones K, Daniels H, Heys S, Lacey A, Ford DV. Toward a risk-utility data governance framework for research using genomic and phenotypic data in safe havens: multifaceted review. *J Med Internet Res* 2020 May 15;22(5):e16346 [FREE Full text] [doi: [10.2196/16346](https://doi.org/10.2196/16346)] [Medline: [32412420](https://pubmed.ncbi.nlm.nih.gov/32412420/)]
174. Riggs ER, Azzariti DR, Niehaus A, Goehringer SR, Ramos EM, Rodriguez LL, Clinical Genome Resource Education Working Group. Development of a consent resource for genomic data sharing in the clinical setting. *Genet Med* 2019 Jan 13;21(1):81-88 [FREE Full text] [doi: [10.1038/s41436-018-0017-5](https://doi.org/10.1038/s41436-018-0017-5)] [Medline: [29899502](https://pubmed.ncbi.nlm.nih.gov/29899502/)]
175. Bernaerd J, Moerenhout T, Devisch I. Vulnerable patients' attitudes towards sharing medical data and granular control in patient portal systems: an interview study. *J Eval Clin Pract* 2021 Apr 04;27(2):429-437. [doi: [10.1111/jep.13465](https://doi.org/10.1111/jep.13465)] [Medline: [32886953](https://pubmed.ncbi.nlm.nih.gov/32886953/)]
176. Nelson D, Spieker M, Hesse B. Communicating health data. *Int Public Health J* 2011;3(2):151-165.
177. Lucero RJ, Kearney J, Cortes Y, Arcia A, Appelbaum P, Fernández RL, et al. Benefits and risks in secondary use of digitized clinical data: views of community members living in a predominantly ethnic minority urban neighborhood. *AJOB Empir Bioeth* 2015 Sep 11;6(2):12-22 [FREE Full text] [doi: [10.1080/23294515.2014.949906](https://doi.org/10.1080/23294515.2014.949906)] [Medline: [26101782](https://pubmed.ncbi.nlm.nih.gov/26101782/)]
178. Piel F, Parkes B, Daby H, Hansell A, Elliott P. The challenge of opt-outs from NHS data: a small-area perspective. *J Public Health (Oxf)* 2018 Dec 01;40(4):e594-e600 [FREE Full text] [doi: [10.1093/pubmed/fdy059](https://doi.org/10.1093/pubmed/fdy059)] [Medline: [29590471](https://pubmed.ncbi.nlm.nih.gov/29590471/)]
179. Rake E, van Gelder MM, Grim D, Heeren B, Engelen L, van de Belt TH. Personalized consent flow in contemporary data sharing for medical research: a viewpoint. *Biomed Res Int* 2017;2017:7147212 [FREE Full text] [doi: [10.1155/2017/7147212](https://doi.org/10.1155/2017/7147212)] [Medline: [28638834](https://pubmed.ncbi.nlm.nih.gov/28638834/)]
180. Shah M, Li C, Sheng M, Zhang Y, Xing C. CrowdMed: a blockchain-based approach to consent management for health data sharing. In: *Smart Health*. Cham: Springer; 2019.
181. Ballantyne A, Schaefer GO. Consent and the ethical duty to participate in health data research. *J Med Ethics* 2018 Jun 22;44(6):392-396. [doi: [10.1136/medethics-2017-104550](https://doi.org/10.1136/medethics-2017-104550)] [Medline: [29358219](https://pubmed.ncbi.nlm.nih.gov/29358219/)]
182. Amr A, Hinderer M, Griebel L, Deuber D, Egger C, Sedaghat-Hamedani F, et al. Controlling my genome with my smartphone: first clinical experiences of the PROMISE system. *Clin Res Cardiol* 2022 Jun 25;111(6):638-650 [FREE Full text] [doi: [10.1007/s00392-021-01942-8](https://doi.org/10.1007/s00392-021-01942-8)] [Medline: [34694434](https://pubmed.ncbi.nlm.nih.gov/34694434/)]
183. Romano V, Milne R, Mascalconi D. Italian public's views on sharing genetic information and medical information: findings from the 'Your DNA, Your Say' study. *Wellcome Open Res* 2021 Jul 12;6:180 [FREE Full text] [doi: [10.12688/wellcomeopenres.16909.1](https://doi.org/10.12688/wellcomeopenres.16909.1)] [Medline: [35233468](https://pubmed.ncbi.nlm.nih.gov/35233468/)]
184. Mählmann L, Schee Gen Halfmann S, von Wyl A, Brand A. Attitudes towards personal genomics and sharing of genetic data among older swiss adults: a qualitative study. *Public Health Genomics* 2017;20(5):293-306. [doi: [10.1159/000486588](https://doi.org/10.1159/000486588)] [Medline: [29414817](https://pubmed.ncbi.nlm.nih.gov/29414817/)]
185. Neves AL, Poovendran D, Freise L, Ghafur S, Flott K, Darzi A, et al. Health care professionals' perspectives on the secondary use of health records to improve quality and safety of care in England: qualitative study. *J Med Internet Res* 2019 Sep 26;21(9):e14135 [FREE Full text] [doi: [10.2196/14135](https://doi.org/10.2196/14135)] [Medline: [31573898](https://pubmed.ncbi.nlm.nih.gov/31573898/)]
186. James R, Tsosie R, Sahota P, Parker M, Dillard D, Sylvester I, Kiana Group. Exploring pathways to trust: a tribal perspective on data sharing. *Genet Med* 2014 Nov;16(11):820-826 [FREE Full text] [doi: [10.1038/gim.2014.47](https://doi.org/10.1038/gim.2014.47)] [Medline: [24830328](https://pubmed.ncbi.nlm.nih.gov/24830328/)]
187. schraefel M, Gomer R, Alan A, Gerding E, Maple C. The internet of things. *Interactions* 2017 Oct 25;24(6):26-33. [doi: [10.1145/3149025](https://doi.org/10.1145/3149025)]
188. Hripcsak G, Bloomrosen M, Flatley Brennan P, Chute CG, Cimino J, Detmer DE, et al. Health data use, stewardship, and governance: ongoing gaps and challenges: a report from AMIA's 2012 Health Policy Meeting. *J Am Med Inform Assoc* 2014;21(2):204-211 [FREE Full text] [doi: [10.1136/amiainjnl-2013-002117](https://doi.org/10.1136/amiainjnl-2013-002117)] [Medline: [24169275](https://pubmed.ncbi.nlm.nih.gov/24169275/)]

189. Jamal L, Sapp JC, Lewis K, Yanes T, Facio FM, Biesecker LG, et al. Research participants' attitudes towards the confidentiality of genomic sequence information. *Eur J Hum Genet* 2014 Aug 27;22(8):964-968 [FREE Full text] [doi: [10.1038/ejhg.2013.276](https://doi.org/10.1038/ejhg.2013.276)] [Medline: [24281371](https://pubmed.ncbi.nlm.nih.gov/24281371/)]
190. Jagsi R, Griffith KA, Jones RD, Krenz C, Gornick M, Spence R, et al. Effect of public deliberation on patient attitudes regarding consent and data use in a learning health care system for oncology. *J Clin Oncol* 2019 Dec 01;37(34):3203-3211. [doi: [10.1200/jco.19.01693](https://doi.org/10.1200/jco.19.01693)]
191. Braunack-Mayer A, Fabrianesi B, Street J, O'Shaughnessy P, Carter SM, Engelen L, et al. Sharing government health data with the private sector: community attitudes survey. *J Med Internet Res* 2021 Oct 01;23(10):e24200 [FREE Full text] [doi: [10.2196/24200](https://doi.org/10.2196/24200)] [Medline: [34596573](https://pubmed.ncbi.nlm.nih.gov/34596573/)]
192. Buhr L, Schicktanz S, Nordmeyer E. Attitudes toward mobile apps for pandemic research among smartphone users in Germany: national survey. *JMIR Mhealth Uhealth* 2022 Jan 24;10(1):e31857 [FREE Full text] [doi: [10.2196/31857](https://doi.org/10.2196/31857)] [Medline: [35072646](https://pubmed.ncbi.nlm.nih.gov/35072646/)]
193. Downing NR, Williams JK, Daack-Hirsch S, Driessnack M, Simon CM. Genetics specialists' perspectives on disclosure of genomic incidental findings in the clinical setting. *Patient Educ Couns* 2013 Jan;90(1):133-138 [FREE Full text] [doi: [10.1016/j.pec.2012.09.010](https://doi.org/10.1016/j.pec.2012.09.010)] [Medline: [23068909](https://pubmed.ncbi.nlm.nih.gov/23068909/)]
194. Paprica PA, de Melo MN, Schull MJ. Social licence and the general public's attitudes toward research based on linked administrative health data: a qualitative study. *CMAJ Open* 2019 Feb 03;7(1):E40-E46 [FREE Full text] [doi: [10.9778/cmajo.20180099](https://doi.org/10.9778/cmajo.20180099)] [Medline: [30718354](https://pubmed.ncbi.nlm.nih.gov/30718354/)]
195. Amorim M, Silva S, Machado H, Teles EL, Baptista MJ, Maia T, et al. Benefits and risks of sharing genomic data for research: comparing the views of rare disease patients, informal carers and healthcare professionals. *Int J Environ Res Public Health* 2022 Jul 19;19(14):8788 [FREE Full text] [doi: [10.3390/ijerph19148788](https://doi.org/10.3390/ijerph19148788)] [Medline: [35886636](https://pubmed.ncbi.nlm.nih.gov/35886636/)]
196. Aggarwal R, Farag S, Martin G, Ashrafian H, Darzi A. Patient perceptions on data sharing and applying artificial intelligence to health care data: cross-sectional survey. *J Med Internet Res* 2021 Aug 26;23(8):e26162 [FREE Full text] [doi: [10.2196/26162](https://doi.org/10.2196/26162)] [Medline: [34236994](https://pubmed.ncbi.nlm.nih.gov/34236994/)]
197. Alrefaei AF, Hawsawi YM, Almaleki D, Alafif T, Alzahrani FA, Bakhrebah MA. Genetic data sharing and artificial intelligence in the era of personalized medicine based on a cross-sectional analysis of the Saudi human genome program. *Sci Rep* 2022 Jan 26;12(1):1405 [FREE Full text] [doi: [10.1038/s41598-022-05296-7](https://doi.org/10.1038/s41598-022-05296-7)] [Medline: [35082362](https://pubmed.ncbi.nlm.nih.gov/35082362/)]
198. Belfrage S, Helgesson G, Lynøe N. Trust and digital privacy in healthcare: a cross-sectional descriptive study of trust and attitudes towards uses of electronic health data among the general public in Sweden. *BMC Med Ethics* 2022 Mar 04;23(1):19 [FREE Full text] [doi: [10.1186/s12910-022-00758-z](https://doi.org/10.1186/s12910-022-00758-z)] [Medline: [35246118](https://pubmed.ncbi.nlm.nih.gov/35246118/)]
199. Milne R, Morley KI, Almarri MA, Atutornu J, Baranova EE, Bevan P, et al. Return of genomic results does not motivate intent to participate in research for all: perspectives across 22 countries. *Genet Med* 2022 May;24(5):1120-1129 [FREE Full text] [doi: [10.1016/j.gim.2022.01.002](https://doi.org/10.1016/j.gim.2022.01.002)] [Medline: [35125311](https://pubmed.ncbi.nlm.nih.gov/35125311/)]
200. Martani A, Egli SM, Geneviève LD, Elger BS, Wangmo T. A role-model for data policies? Qualitative study on the governance of health data in Denmark. *Health Policy Technol* 2022 Dec;11(4):100683. [doi: [10.1016/j.hlpt.2022.100683](https://doi.org/10.1016/j.hlpt.2022.100683)]
201. Austin CC, Bernier A, Bezuidenhout L, Bicarregui J, Biro T, Cambon-Thomsen A, Research Data Alliance. Fostering global data sharing: highlighting the recommendations of the Research Data Alliance COVID-19 working group. *Wellcome Open Res* 2020 May 26;5:267 [FREE Full text] [doi: [10.12688/wellcomeopenres.16378.2](https://doi.org/10.12688/wellcomeopenres.16378.2)] [Medline: [33501381](https://pubmed.ncbi.nlm.nih.gov/33501381/)]
202. Mascalonzi D, Melotti R, Pattaro C, Pramstaller PP, Gögele M, De Grandi A, et al. Ten years of dynamic consent in the CHRIS study: informed consent as a dynamic process. *Eur J Hum Genet* 2022 Dec 05;30(12):1391-1397 [FREE Full text] [doi: [10.1038/s41431-022-01160-4](https://doi.org/10.1038/s41431-022-01160-4)] [Medline: [36064788](https://pubmed.ncbi.nlm.nih.gov/36064788/)]
203. Public consultation on transformation of health and care in the digital single market. European Commission. 2017. URL: https://ec.europa.eu/info/consultations/public-consultation-transformation-health-and-care-digital-single-market_en [accessed 2022-03-02]
204. Caron D, Hunt T. Accountability and disclosure: the proper use of transparency instruments and their implications for canadian public administration. In: Proceedings of the Third Regional International Conference on Administration Sciences: Transparency for Better Governance. 2006 Presented at: Third Regional International Conference on Administration Sciences: Transparency for Better Governance; Jul 16–20, 2006; Monterrey, Mexico.
205. Kalkman S, van Delden J, Banerjee A, Tyl B, Mostert M, van Thiel G. Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence. *J Med Ethics* 2022 Jan;48(1):3-13 [FREE Full text] [doi: [10.1136/medethics-2019-105651](https://doi.org/10.1136/medethics-2019-105651)] [Medline: [31719155](https://pubmed.ncbi.nlm.nih.gov/31719155/)]
206. Muller SH, Kalkman S, van Thiel GJ, Mostert M, van Delden JJ. The social licence for data-intensive health research: towards co-creation, public value and trust. *BMC Med Ethics* 2021 Aug 10;22(1):110 [FREE Full text] [doi: [10.1186/s12910-021-00677-5](https://doi.org/10.1186/s12910-021-00677-5)] [Medline: [34376204](https://pubmed.ncbi.nlm.nih.gov/34376204/)]
207. Social licence for uses of health data: a report on public perspectives. Health Data Research Network Canada. URL: <https://www.hdrn.ca/en/reports/social-licence-uses-health-data-report-public-perspectives> [accessed 2023-02-02]
208. Ford E, Stanley K, Rees-Roberts M, Madzvamuse A, Armes J, Giles S. Co-creating a social licence for using novel linked datasets for planning and research in Kent, Surrey and Sussex: results of deliberative focus groups and a creative workshop. *Int J Population Data Sci* 2022 Aug 25;7(3). [doi: [10.23889/ijpds.v7i3.2109](https://doi.org/10.23889/ijpds.v7i3.2109)]

209. Wilkins CH, Mapes BM, Jerome RN, Villalta-Gil V, Pulley JM, Harris PA. Understanding what information is valued by research participants, and why. *Health Aff (Millwood)* 2019 Mar;38(3):399-407 [FREE Full text] [doi: [10.1377/hlthaff.2018.05046](https://doi.org/10.1377/hlthaff.2018.05046)] [Medline: [30830824](https://pubmed.ncbi.nlm.nih.gov/30830824/)]
210. Goodman D, Bowen D, Wenzel L, Tehrani P, Fernando F, Khacheryan A, et al. The research participant perspective related to the conduct of genomic cohort studies: a systematic review of the quantitative literature. *Transl Behav Med* 2018 Jan 29;8(1):119-129 [FREE Full text] [doi: [10.1093/tbm/ibx056](https://doi.org/10.1093/tbm/ibx056)] [Medline: [29385589](https://pubmed.ncbi.nlm.nih.gov/29385589/)]
211. Recommandations pour assurer le bon fonctionnement d'un centre d'accès aux données pour la recherche au sein d'un organisme public. Fonds de recherche du Québec. 2022 Apr. URL: http://scientifique-en-chef.gouv.qc.ca/wp-content/uploads/Recommandations-pour-les-Centres-dacces-aux-donnees-Comite-chercheur.se.s-FRQ_V1_Avril-2022.pdf [accessed 2022-11-04]
212. Karrar N, Khan S, Manohar S, Quattroni P, Seymour D, Varma S, The UK Health Data Research Alliance. Improving transparency in the use of health data for research: recommendations for a data use register standard. Zenodo. 2022. URL: <https://doi.org/10.5281/zenodo.5902743> [accessed 2022-11-04]
213. Caron DJ, Montmarquette C, Prud'homme A, Bernardi S, Nicolini V. Projet sur l'acceptabilité sociale du partage des renseignements de santé : enquête sur l'acceptabilité sociale du partage des renseignements de santé : constatations, résultats et variations : rapport final. Canada: Research Chair in Information Resources Exploitation, ENAP; 2020.
214. Upshur RE, Goel V. The health care information directive. *BMC Med Inform Decis Mak* 2001 Apr 25;1(1):1 [FREE Full text] [doi: [10.1186/1472-6947-1-1](https://doi.org/10.1186/1472-6947-1-1)] [Medline: [11331535](https://pubmed.ncbi.nlm.nih.gov/11331535/)]
215. Vaisson G, Provencher T, Dugas M, Trottier M, Chipenda Dansokho S, Colquhoun H, et al. User involvement in the design and development of patient decision aids and other personal health tools: a systematic review. *Med Decis Making* 2021 Mar 03;41(3):261-274. [doi: [10.1177/0272989x20984134](https://doi.org/10.1177/0272989x20984134)]
216. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping patients decide: ten steps to better risk communication. *J Natl Cancer Inst* 2011 Oct 05;103(19):1436-1443 [FREE Full text] [doi: [10.1093/jnci/djr318](https://doi.org/10.1093/jnci/djr318)] [Medline: [21931068](https://pubmed.ncbi.nlm.nih.gov/21931068/)]
217. Zikmund-Fisher BJ. The right tool is what they need, not what we have: a taxonomy of appropriate levels of precision in patient risk communication. *Med Care Res Rev* 2013 Feb 06;70(1 Suppl):37S-49S. [doi: [10.1177/1077558712458541](https://doi.org/10.1177/1077558712458541)] [Medline: [22955699](https://pubmed.ncbi.nlm.nih.gov/22955699/)]
218. Registry - do the research your community cares about. Genetic Alliance. URL: <https://geneticalliance.org/registries/ga-registry> [accessed 2022-11-08]
219. The future of health begins with you. National Institutes of Health All of Us Research Program. URL: <https://allofus.nih.gov/future-health-begins-all-us> [accessed 2022-11-04]
220. Connect care. Alberta Health Services. URL: <https://www.albertahealthservices.ca/cis/cis.aspx> [accessed 2022-11-04]
221. Background. sundhed.dk. URL: <https://www.sundhed.dk/borger/service/om-sundheddk/om-organisationen/ehealth-in-denmark/background/> [accessed 2022-11-04]
222. Health Data Hub homepage. Health Data Hub. URL: <https://www.health-data-hub.fr/> [accessed 2022-11-04]
223. The First Nations Information Governance Centre homepage. The First Nations Information Governance Centre. URL: <https://fnigc.ca/> [accessed 2022-10-26]
224. Lang M, Lemieux S, Hébert J, Sauvageau G, Zawati M. Legal and ethical considerations for the design and use of web portals for researchers, clinicians, and patients: scoping literature review. *J Med Internet Res* 2021 Nov 11;23(11):e26450 [FREE Full text] [doi: [10.2196/26450](https://doi.org/10.2196/26450)] [Medline: [34762055](https://pubmed.ncbi.nlm.nih.gov/34762055/)]

Abbreviations

LHS: learning health system

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews

Edited by A Mavragani; submitted 12.12.22; peer-reviewed by D Willison, J van Delden; comments to author 25.01.23; revised version received 09.02.23; accepted 03.03.23; published 13.04.23

Please cite as:

Cumyn A, Ménard JF, Barton A, Dault R, Lévesque F, Ethier JF

Patients' and Members of the Public's Wishes Regarding Transparency in the Context of Secondary Use of Health Data: Scoping Review

J Med Internet Res 2023;25:e45002

URL: <https://www.jmir.org/2023/1/e45002>

doi: [10.2196/45002](https://doi.org/10.2196/45002)

PMID: [37052967](https://pubmed.ncbi.nlm.nih.gov/37052967/)

©Annabelle Cumyn, Jean-Frédéric Ménard, Adrien Barton, Roxanne Dault, Frédérique Lévesque, Jean-François Ethier. Originally published in the Journal of Medical Internet Research (<https://www.jmir.org>), 13.04.2023. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in the Journal of Medical Internet Research, is properly cited. The complete bibliographic information, a link to the original publication on <https://www.jmir.org/>, as well as this copyright and license information must be included.