

Patient and family engagement in health information technology initiatives: Findings of a literature review, focus groups and symposium

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Executive summary

The CIHR's Strategy for Patient Outcome Research (SPOR) describes patient engagement as meaningful collaboration, through which patients can be actively engaged in governance, priority setting, defining the problem and in some cases conducting certain parts of the project itself.¹ Patient engagement is one strategy that may be used to achieve the goals of improved health outcomes and provision of better patient care. Several studies have shown that promising outcomes can be obtained from health information technologies (IT) when patients and family members are effectively engaged in different phases of health IT initiatives.²⁻⁴ However, many of the potential benefits of health IT innovations to patients, families and the Canadian health care system remain unseen.

This report summarizes the results and findings of three research activities:

- **a literature review** conducted to identify academic articles and grey literature that aim to improve outcomes of health IT initiatives by engaging patients and families
- **focus groups** conducted to learn the perceptions of patients and family members on the topic of patient engagement in health IT initiatives
- **a one-day symposium** hosted to disseminate research findings and engage in further discussions to refine and contextualize identified engagement strategies.



The goal of this report is to inform the development of a future resource document that will guide engagement plans employed by health care organizations in health IT initiatives.

Section 1

Introduction and background

What is patient engagement?

There are numerous definitions for patient engagement and related terms. Patient engagement is often used as a broad concept that combines a patient's knowledge, skills, ability and willingness to manage his or her own health and care.⁵ The Patient-Centered Outcomes Research Institute (PCORI) in the United States defines "patient partners" as a broad term that encompasses patients, family members, caregivers and organizations that are representative of the population of interest.⁶ The Canadian Institutes of Health Research's Strategy for Patient Outcome Research (SPOR) describes patient engagement as meaningful collaboration, where patients can be actively engaged in governance, priority setting, defining the problem and in some cases conducting certain parts of the project itself.¹

Patient engagement helps ensure that health care projects and decisions are relevant and valuable to the affected audience: patients.¹ In place of the notion that patients are consumers of health services, patient engagement positions patients as active partners in their care. As a result, many health care organizations are employing strategies to better engage patients, such as

educating patients about their health and involving patients in decision making about their care plan.⁵

What is health information technology?

Health information technologies (IT) refers to various forms of technologies used to store, share and analyze information in health contexts.⁷

Examples of health IT include electronic health records, patient portals and mobile health applications. Electronic health records provide digital access to



patient records,⁸ which may contain information such as diagnostic images, previous medical history, medications, allergies, clinical documentation and discharge summaries.⁹ Patient portals are secure websites that can offer a variety of functions to patients, such as access to their medical records, and the ability to schedule appointments and communicate with health professionals.^{10,11}

The stages of a typical health IT development and implementation project¹² may include:

- gathering of requirements
- design
- development
- implementation
- use and adoption
- evaluation.

Why engage patients in health IT projects?

Technological advancements have provided increased opportunities for patients to access health information and be informed about their care.¹³ Electronic health record systems and related technologies have been adopted by many health care organizations across Canada and internationally, in an effort to improve the efficiency and effectiveness of health service delivery.^{14,15} A growing number of health care organizations have also implemented patient portals, which are tethered to electronic health records and improve patient access to health information.^{11,16}

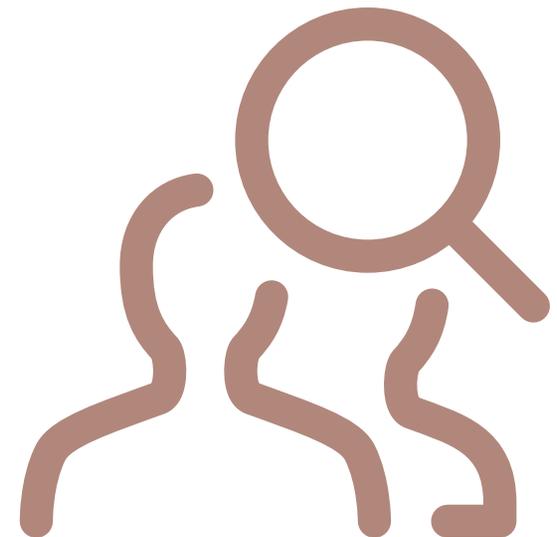
Several studies have shown that encouraging outcomes can be obtained from health IT projects when patients and family members are effectively engaged in their adoption, implementation and evaluation.²⁻⁴ However, health care organizations have

not consistently taken full advantage of these technological innovations, and so many possible benefits of health IT to patients, families and the Canadian health care system remain unseen.¹⁷

Goals of this document

The goals of this document are to provide health care organizations with:

- findings from studies that have improved health outcomes through patient and family engagement
- an outline of practical strategies to effectively engage patients and family members
- recommendations for the development of a resource to guide engagement plans employed by health care organizations.



The need for a resource on engaging patients in health IT

Despite the need to engage patients and families in health IT initiatives, there is a lack of resources to guide health care organizations in planning and executing engagement strategies. A resource document can provide evidence-based engagement strategies and recommendations, allowing Canadian health care organizations to effectively engage patients and families to realize the benefits of health IT innovations.

The proposed resource document will be intended for use by health care organizations, health authorities and government agencies. Stakeholders who may find it useful include administrators in information management and clinical operations, health professionals, health informatics specialists and project managers involved with health IT initiatives.



Section 2

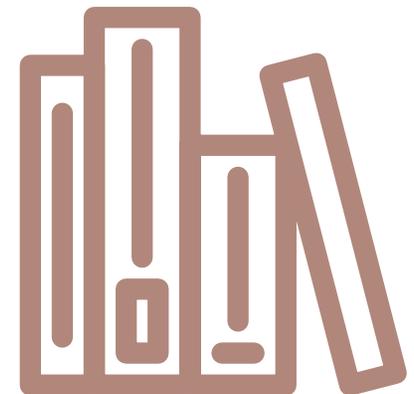
Methods

The data detailed in this report have been collected through various approaches:

- **A literature review** was conducted to identify academic articles and grey literature that have outlined effective approaches to meaningfully engage patients and families.
- **Focus groups** were conducted to obtain the perspectives of consumers of Canadian health services and family members.¹⁸
- **A symposium** was held to disseminate pertinent research findings and to facilitate a discussion among patients, family members, health professionals, researchers and knowledge users, on items that can be used to inform the development of a resource document. (Knowledge users may include individuals in a variety of roles, such as clinical informatics, project management, professional practice and other health professionals.)

Literature review

A review of existing literature on the use of patient engagement strategies was conducted using a scoping review methodology. Scoping reviews, like systematic reviews, are an approach to reviewing research evidence. Unlike systematic reviews, however, scoping reviews do not assess the quality of each study.¹⁹ They are often considered as a means of mapping a range of evidence from various study designs in both academic and grey literature. This can be helpful in disseminating knowledge from a heterogeneous evidence base.^{20,21} The design of this review was informed by the framework developed by Arksey and O'Malley, and further refined by Levac et al.^{19,22}



Stage 1 Identifying the research questions

The literature review was intended to answer the following research questions:

1. What existing frameworks have been used to effectively guide patient and family engagement in the adoption, use, implementation, selection and evaluation of health IT?
2. What studies have been done on effective patient and family engagement strategies in the adoption, use and evaluation of health IT? What are their results?
3. What patient and family engagement frameworks (not specific to health IT), studies and resources can be applied to health IT adoption, use and evaluation?

In developing the research questions, the following assumptions were made in clarifying the terminology used in studies:

- The term “framework” refers broadly to the description, identification or simplification of relevant elements to explain and understand a phenomenon of interest.^{23,24}
- The term “health information technology” refers to various forms of information technologies used in health contexts such

as electronic health records, patient portals and mobile health applications.

The research questions were outlined and refined through consultation with the research team and a patient and family advisory committee.

Stage 2 Identifying relevant studies

All research, editorial and opinion papers were included within this scoping review. Studies and frameworks in any clinical or health care setting were included. The studies and documents assessed were not limited by their date of publication or country of origin. However, studies published in languages other than English were excluded.

With the guidance and support of a research librarian with experience in conducting scoping reviews, a search strategy was developed using the following electronic databases: Medline, PsycINFO, CINAHL, Theses Canada and the Education Resources Information Center (ERIC). A primary search strategy was developed for the Medline database, and was adapted for use with the other databases. The search was refined using specific search terms such as “electronic health records,” “patient portals,” “toolkits,” “resource” and “strategies.”

The database search was supplemented with a search for grey literature related to patient engagement frameworks and toolkits, using the Google search engine and the Canadian Agency for Drugs and Technologies in Health Grey Matters search tool.

Stage 3 Study selection

In total, 852 articles were retrieved from the database search. To select the studies relevant to this particular review, two members of the research team independently screened the titles and abstracts of the retrieved studies for eligibility. Strategies outlined by studies had to be relevant to any clinical or health care setting. Systematic reviews and other types of literature reviews were not considered eligible, but their references were screened to find supplementary relevant studies.

The reviewers used Covidence screening and data extraction software to track duplicate articles and facilitate the screening process.²⁵ The software identified 66 duplicates, which were removed from the retrieved studies. Upon screening the articles, an additional three duplicates were found and removed.

For each remaining article, the reviewers determined if inclusion criteria were met, and where relevant indicated the primary reason for exclusion. After all the articles were independently screened, the two reviewers met and resolved any conflicting findings. When a conflict could not be resolved, a third member of the research team was consulted. The articles that passed the first stage of title and abstract screening were read in full and screened for eligibility. During the full text screening process, the inter-rater reliability (measured as percentage agreement between the two reviewers) was greater than 75%.

Stage 4 Charting the data

Data from selected articles pertinent to the research questions were extracted, and this information was charted and summarized. It included:

- descriptive data of the study (study name, authorship, country of publication, journal in which published, study design, study setting and target population of study)
- study methods (engagement strategies employed by researchers)
- study results (proposed framework and lessons learned from the methodology).

For the first 10 studies, two members of the research team extracted data independently, and then met to determine whether the categories corresponded to the three research questions. The format of the data table was then refined as needed.



Stage 5

Collating, summarizing and reporting the results

The extracted data were then organized in broad categories based on the research question that the relevant article addressed. The patient engagement strategies and considerations recommended in the articles were recorded. Patient and family engagement studies and frameworks specific to health IT were separated from general patient, consumer or stakeholder engagement studies, resources and frameworks. A descriptive analysis of framework elements was provided. Common engagement strategies were counted and described.

Focus group

Two focus groups were conducted with the goal of obtaining the perspectives of patients and family members, respectively, on engagement in the selection, adoption, use and evaluation of health IT. To be included in the patient group, participants needed to be consumers of health services in Canada. To be included in the family member group, participants needed to be family members of someone who has used health services in Canada. Five participants were recruited for each group.

The focus groups took place at a large academic hospital in Toronto, and were co-facilitated by two members of the research team. A focus group guide was developed, which included six main questions with prompts. These questions were intended to elicit an understanding of participants' perspectives and experiences with engagement in a health care context, and to garner recommendations for engagement strategies.

The focus groups were recorded, and the audio recordings were transcribed verbatim and checked for accuracy by an investigator. Inductive content analysis was used in an iterative process to code the transcripts and create an abstraction of categories and themes. For the first focus group, two members of the research team performed the inductive content analysis independently, and met to compare their results. Disagreements were addressed through discussion until a resolution was found. The two researchers then coded the transcript of the second focus group, and met to compare their results and create the second iteration of categories and definitions. This was then used to recode the first group. The researchers met a final time to discuss their results and create the final iteration of categories and definitions.

Symposium

The symposium was a one-day event that took place at an academic hospital in Toronto. A diverse audience, including patients, family members, health professionals, health administrators, informatics researchers and students, was asked to participate. The morning session began with a keynote address by one of the members of the research team. Following this, a panel of patients, family members and health professionals who engage in informatics-related projects shared their experiences and engaged the audience in a question-and-answer session. Finally, a member of the research team disseminated the research findings that emerged from the literature review and focus groups to the symposium participants.

The afternoon session opened with a group priority sort activity.²⁶ Participants were divided into groups of five or six members reflecting the diversity of those present at the symposium. A facilitator and a note-taker were assigned to each group. The

facilitator provided the instructions for the activity and presented the group with 30 index cards. Each card revealed a unique element of engagement that was outlined in the findings of the previous research activities. The facilitators then prompted each participant to quickly rate each item on a five-point Likert scale (1 being the least important and 5 being the most important), based on the priority the item should be assigned if it were included in the developed resource document. Once all 30 index cards were rated, the participants in the groups were asked to brainstorm additional items they thought were missing. All participant ratings and additional items were recorded by the note-taker.

Next, the participants were asked to brainstorm knowledge translation methods, and formatting and other related requirements, that should be considered for the development of the proposed resource document. The facilitators prompted the participants to be as detailed as possible when brainstorming ideas.



Finally, five cards were set out, each representing a number on the five-point Likert scale. Each group was asked to achieve consensus in sorting the 30 index cards, and any additional cards, into the five-point Likert scale. Six cards had to be assigned to each number on the Likert scale (1 to 5); if the group had generated additional cards, it was permissible to assign seven cards to some numbers on the scale. The facilitator and the note-taker engaged all participants in the group to think critically in sorting the cards, and ensured that all opinions were heard. The main goal of this last activity was to identify relative priorities through the imposition of strict parameters.

At the end of the symposium, participants were asked to complete a brief paper evaluation survey comprised mainly of questions with rating elements. Participants were also asked to complete a subsequent online survey, which was sent out via email on the day after the symposium, and which comprised more open-ended questions on participants' overall experience of the event, and elements that could be improved upon.

Section 3

Results

Literature review

A total of 54 relevant articles or documents were identified (including both academic and grey literature). Thirty-three academic articles met the inclusion criteria. As outlined in Table 1, of the 33 articles, one study was a randomized controlled trial, 10 were reports, editorials or evidence-based papers, 21 were qualitative studies, and one was a mixed method study. The studies were conducted mainly in the United States; the remaining publications originated in other countries in North America, Europe and Asia. The major stakeholders or populations engaged in the literature were patients, caregivers or health care professionals. Studies related to health IT included those that evaluated the implementation of electronic health record systems and of ambulatory and inpatient portals. Studies conducted in non-clinical settings were set in a research context and engaged participants in the development, execution and evaluation of research projects.

In addition to the articles, 21 documents were identified from the grey literature search. Thirteen documents were published in Canada, three in the United Kingdom, three in the United States, and four in Australia.

Table 1

Study design of studies and documents identified through the scoping review

Type of study design	Number of studies/ documents (n = 54)
Quantitative	1
Qualitative	21
Mixed methods	1
Reports, editorials and evidence-based papers	10
Reports, websites and other forms of grey literature	21

Research question 1: What existing frameworks have been used to effectively guide patient and family engagement in the adoption, use, implementation, selection and evaluation of health IT?

Two academic articles outlined frameworks that have been used to guide patient and family engagement in the adoption,

use, implementation, selection and evaluation of health IT. The framework proposed by Carman et al. outlines approaches to engagement that align with the International Association for Public Participation's spectrum for community engagement. This framework also outlines three categories that segment different levels of the health care system as follows: individual care, organization governance and government policy.^{27,28} At the institutional level, health care organizations and staff can encourage patient engagement by demonstrating that patient participation and leadership is imperative to the achievement of organizational goals.²⁷ At the government level, policy-makers can create mechanisms to allow patients to be active participants in developing public policy through public deliberation sessions, town hall meetings and public hearings.²⁷

A study by Walker et al. outlines a model to evaluate an inpatient portal.²⁹ The model shows that because multiple stakeholders are involved in implementing and using an inpatient portal, all perspectives should be accounted for. The model also demonstrates how training and technical support are critical to the success with which a patient portal is implemented.³⁰

Research question 2: What studies have been done on effective patient and family engagement strategies in the adoption, use and evaluation of health IT? What are their results?

Nineteen studies were identified that used patient and family engagement strategies in health IT adoption, use and evaluation. One study highlights that alternative channels of engagement are needed for vulnerable patient populations who may be affected by existing social disparities.³¹ Several studies suggest an interdisciplinary team-based approach as an effective strategy for

patient and family engagement.^{32–34} Results from a study by Raval et al. conclude that the engagement of a pediatric surgeon and physician assistant was crucial to the success of engaging patients.³³ Likewise, a study by Krist et al. concluded that a team approach to engaging patients positively influenced the uptake of the patient portal compared to a health professional-dependent approach to engaging patients.³²

Eight articles highlighted the importance of training in the success of health IT adoption, implementation and use. A randomized controlled trial conducted by Greysen et al. suggests that portal training produced an increased ability to log in and navigate the portal, greater satisfaction with portal use and higher frequency of portal use after discharge.³⁵ A study by Wildenbos et al. concludes that patients' health literacy level strongly influenced their overall interest in using a hospital's patient portal.³⁶ Wildenbos et al. and Metting et al. both recommend a focus on training and supporting providers in their interactions with patients via the portal.^{36,37} The study by Metting et al. also explored patients' needs and opinions through focus group meetings to facilitate the development of patient portals.



Research question 3: What patient and family engagement frameworks (not specific to health IT), studies and resources can be applied to health IT adoption, use and evaluation?

There were 12 academic articles that employed patient and family engagement strategies for research and clinical projects. Commonly recommended strategies identified in these articles are summarized in Table 2.

Table 2
Common strategies recommended to effectively engage patients and family members in identified academic literature

1. Provide adequate preparation training for both the engaged stakeholders and the team members engaging stakeholders^{29,33-44}
2. Engage stakeholders early in the development stage of the project^{41,42,45-47}
3. Provide stakeholders with clear expectations, roles and responsibilities^{40,42,44,45,47}
4. Develop policy or practice that provides incentive or compensation to stakeholders for their time and efforts^{39,40,42,44,48}
5. Prioritize effective communication with regular updates, explain research and medical terminology, and show that patients are valued as partners^{45,47,49-51}
6. Be transparent about patients' contributions being used and making an impact on the project^{42,43,47,52}
7. Leverage health professionals as trusted agents^{33,48,53,54}
8. Meet with stakeholders at time and location that is convenient to them^{39,43,47,55}
9. Engage patients in groups of three or more so they can encourage each other and benefit from shared discussion^{40,46,56}
10. Use established networks of stakeholder groups^{42,43,45}

Twenty-one reports identified in the grey literature highlighted considerations for patient engagement in the health care and research context (see Table 3).

Table 3
Considerations highlighted in existing engagement frameworks, resources and toolkits^{1,6,57-75}

1. Preparing and planning for engagement

Involve people as early as possible so they feel part of the research and have a sense of ownership^{64,71,72}

Organize meetings and workshops at appropriate times to make attendance as practical as possible for participants⁷¹

Incorporate multiple phases of engagement, such as the planning, implementation, monitoring and evaluation of projects⁶⁴

Engage people at the planning phase to maximize their opportunity to contribute and shape the outcome⁶⁴

Partner with patient organizations and external agencies to provide knowledge and engage useful contacts⁶⁴

Engage and develop relationships with local community or social service organizations to recruit patients and family members from specific populations⁶⁵

When engaging external organizations, contact the organization through a known colleague⁷¹

Engage an experienced patient champion who can recruit and train additional patient partners⁶⁵

Advertise projects in local newspapers and on social media^{65,69,72}

Include people with a range of culturally and linguistically diverse backgrounds⁶²

Ensure that meeting places are accessible to all stakeholders⁷²

Provide information in person or by telephone in advance of meetings⁷¹

Consider potential barriers to engagement⁶²

Table 3 continued

Have a kickoff meeting to encourage interest and participation among patient and family groups, and gather thoughts from stakeholders on the potential scope of engagement activities⁷¹

Identify the objectives and impact of engagement activities⁶³

Tailor the format and method of engaging stakeholders to suit the context⁶⁰

Determine the appropriate level of engagement to meet patients' and the organization's goals⁶⁰

Have the project team and the engaged population agree upon, clarify and document the stakeholders' roles, responsibilities and scope of the engagement initiative^{64,67,72}

Plan to protect patients' privacy⁶⁵

2. Potential engagement activities

One-on-one interviews can be used to explore an issue in depth with a single patient and help build rapport on an individual basis⁶⁶

Group discussions can be used to gather multiple perspectives on a range of issues that affect a broad audience⁶⁶

Surveys can be used to gather feedback on focused questions from a large number of people⁶⁶

Anonymous comment boxes can allow the public to submit feedback on sensitive issues with minimal time commitment⁶⁶

Co-design techniques can be used to partner with patients and caregivers in designing services⁶⁶

Committees and task forces can be used when various perspectives need to be drawn for a single project⁶⁶

Advisory councils (patient and/or family member) can be used when high-priority, long-term decisions need to be made within an organization⁶⁶

Patients should be involved in key governance structures and decision-making processes (such as steering committees, quality and safety committees, patient and family advisory councils, and patient and family groups)^{1,58,74}

3. Supporting engagement

Integrate patient engagement into existing training strategies (training or educational sessions) for patients¹

Involve the public as conference presenters and co-authors of journal articles^{61,72}

Involve stakeholders in recruiting study participants and developing study materials⁶

Give patients feedback on the impact of their input and any constraints that may have hindered the implementation of their recommendations⁶⁵

Develop a communication plan that can be used throughout the engagement process to communicate with all relevant stakeholders^{60,72}

Write in jargon-free language and accommodate for any accessibility needs⁷²

Be aware that a single patient cannot represent the experience of all patients⁶⁵

Keep contributing members informed about the project through progress reports⁷²

Involve stakeholders in developing the research questions and desired outcomes⁶

Leverage stakeholders in identifying partner organizations for the dissemination of study results⁶

Set up a database of stakeholders, including contact information and areas of interest⁶²

Allocate funds to reimburse participants for expenses^{61,62,65,69,71,72}

Provide teleconferencing facilities so the public can attend meetings remotely⁶²

Solicit patients' feedback in developing educational materials for the target patient audience⁵⁸

Allow for family presence when engaging patients⁵⁸

Explore creative engagement methods to ensure that activities are appropriate for all members of the community⁶⁴

Support patients in sharing the responsibility of reaching out to under-represented groups¹

Table 3 continued

Develop guidelines, policies and procedures to guide transparent and accountable processes^{60,64,70}

Track and update clear timelines for each milestone⁶⁹

Be aware of the major role that health care professionals play in encouraging patients to participate in engagement activities⁵⁹

Communicate clearly to patients the type of patient information collected, who will see the information and, if applicable, why that information is being shared⁶⁵

Ensure that communication is open, respectful and culturally appropriate⁶³

Encourage participation by outlining outcome measures that are important to patients¹

4. Evaluating engagement

Create reporting structures that use multiple communication channels (e.g., written, email, phone, social media) to solicit patients' feedback⁷⁴

Check in with patients frequently for any questions and to evaluate engagement process⁶⁵

Provide thank you letters to each contributing group, along with feedback and suggestions for future involvement⁶⁹

Ensure that the evaluation of engagement activities is built into project plans⁶⁴

Provide evaluation forms or surveys so that patients and family members can provide constructive, anonymous feedback on their experience⁷¹

Discuss the evaluation of engagement activities with patients⁶⁴

In the six months after engagement, leverage existing standardized tools to assess the planning, execution and impact of the engagement^{64,65}

Encourage the use of performance measures and specific objectives to quantify the value of engagement initiatives⁶¹

Focus group

The main findings from the focus group inductive content analysis fall into four broad themes:

- logistical and procedural aspects
- engagement practices
- training for facilitators on engaging patients and family members
- recommendations for engagement.

Logistical and procedural aspects

Payment for time and expertise

During both focus groups, participants emphasized that compensating and acknowledging participants for their time and expertise is important for effective engagement. There were mixed perspectives on how this should be done. One patient participant suggested that participants should be paid equivalent to the pay they may have lost by missing work; one family member participant mentioned that even a small honorarium helps encourage people to participate.

"You can't take people away from their jobs unless they're being compensated the same as their job." — Patient

Method of contacting and recruiting participants

Participants emphasized the need to recruit and engage people belonging to groups that are not regularly involved in health IT projects. Many suggested using social media to market engagement opportunities to engage patients and family members who may not typically be reached. One patient participant suggested using advertisements showcasing the benefits of engaging with health IT, including how it could positively affect one's care.

"You're looking for a particular demographic and if you send it out on a Facebook notification, maybe that would recruit more feedback." — Patient

Time and day

Another logistical aspect was the time and day of the week that engagement occurs. The time and day of meetings or events will largely influence who can participate; participants indicated that to recruit the most participants, engagement times should sometimes be outside regular work hours.

"Time of day is crucial. You can't take people away from their jobs." — Family member

Language barriers

Participants emphasized the need to offer engagement projects in languages other than English. This would broaden the group of potential participants to include people from nationalities and cultures outside of an anglophone demographic. One family member said, "My parents both don't speak English that well, so even though I'm not the one receiving care, I'm usually the one that has to go with them to the appointments and kind of figure out what things mean and what they need to do."

"I find when I participated in other projects, it seemed like it was very catered to English speaking [people]. So . . . you don't get that much diversity [versus what] you would get if you considered other cultures and nationalities to participate as well." — Patient

Considerations for accessibility

The location and format of the method of engagement (e.g., in person, online) will influence who is able to participate. Locations for engagement meetings, events and initiatives should be planned with accessibility in mind. This involves, for example, ensuring that participants with mobility aids, as well as people who live in rural locations, will be able to travel to and from the location. In many cases, it may be necessary to offer meetings online or via teleconference, and to advertise that accommodations are available for people who cannot attend in person.

"I think location's important, too, so [give] thought to [things like] transit systems, accessibility, cost, if there's going to be parking. Okay, is that parking going to cost or is there going to be some complimentary parking for that event? All these different things [are] factors to consider." — Patient

Engagement practices

Communication, follow-up and transparency

Participants in both focus groups said that when engaging participants, strong communication between researchers and participants should be prioritized, along with follow-up and a commitment to transparency about where and how research and engagement findings are being used. The beginning of projects often involves a meeting where high-level ideas are shared and plans are made. However, there often is no follow through or updates afterwards.

A patient said that "Everybody walks away and then there's no accountability, no touch points."

This communication between the groups doing the engaging and the groups being engaged is imperative. Following up with participants and maintaining periodic communication makes the engagement process more enjoyable, encourages thoughtful and meaningful engagement, and increases the likelihood that engagement will occur in the future. Communicating with participants also provides them with some transparency, letting them know how their feedback or insight is being incorporated. One family member expressed that they would like an update: “It’s been six months; this is what we’ve done so far, and this is how we’ve actually used your feedback.”

“It would be great to know what the end result was . . . the result of the study or . . . the result of that input. If they [patients] participated and they [did not] get a follow up as to what the result was, it seems like their recommendation was not considered.” — Patient

Engagement early and throughout the process

Participants indicated that they need to be involved at the beginning of projects, when adoption and selection are occurring, rather than being engaged later when significant decisions have already been made. Depending on the nature of the project, early engagement often allows patients’ and family members’ feedback to have more influence on the project. One patient stated that engagement “at the front end is crucial, because it could mean a lot of wasted time throughout the project” if this were not done. Engagement throughout the process can take the form of email updates, newsletters and follow-up meetings to let the participants know the outcome of their engagement. If participants are not engaged early and throughout the process, researchers run the risk of tokenizing their input and deterring them from participating in future engagement efforts.

“It’s important to include [patients] in the beginning of the project . . . as well as the end. And sadly, for me, I was only participating at the end of the project, so I didn’t get to contribute as to what information, for me as a patient, would be important.” — Patient

Training for facilitators on engagement practices

Participants emphasized that participants’ experiences with in-person engagement are influenced by the facilitator’s ability to lead a discussion, focus group, committee meeting or event. Training on engagement practices (e.g., facilitating a focus group discussion, leading a patient and family advisory committee) for professionals aiming to engage patients and family members would help refine the engagement process and help create an environment that encourages all participants to contribute. A family member stated, “It takes a lot for someone to feel comfortable within their environment [and] to actually speak and communicate.” Training on how to facilitate a meeting and discussion would help optimize participants’ experience of engaging with health IT projects.

“Let’s say someone gets put down for saying something: you’re going to be quiet then from now on.” — Patient

Methods of engagement

Participants in both focus groups suggested a variety of methods of engagement. One suggestion was to include engagement surveys on patient portals, taking advantage of this easy and efficient way of collecting data. Another suggestion, by a family member, was to engage participants as a family unit, an approach that may facilitate a more comfortable environment for candid responses, as

well as providing a space in which people who know each other well can build off one another's ideas. Participants also suggested using government-based survey apps, such as Carrot Rewards, which give incentives to users for filling out health-related surveys.

"Definitely just giving [participants] multiple options . . . in how to best engage. Some people feel more comfortable in person; some people feel more comfortable to be doing something online, as was said. So, just catering to their specific interests and perhaps formats of how to engage as best as possible, I think would be important." — Patient

Symposium

A total of 39 participants attended the symposium. The participants, who had experience in various urban and rural health care settings, consisted of four patients, two family members of patients, nine students, four researchers, nine health professionals, two vendor representatives and nine knowledge users.

Group priority sort results

Of the 30 items that participants ranked to be included in a resource document, the highest in the forced sort were:

1. recognition of power dynamics
2. governance structures.

This indicates that there is a strong need for participants to be respected in their consultative roles, which should be reflected in policy and structure at the institutional level.

Four items ranked equal-third, with an average of 4.00 in the forced sort:

- patient/family member health IT training
- patient/family member engagement in the process of gathering health IT requirements
- engagement training for health care staff
- engagement of patients and family members in health IT evaluation.

These items highlight the importance of training for both patients / family members and professional staff. They also emphasize the necessity for health IT, and its evaluation, to address the needs of patients and family members.

The lowest ranked items included a list of engagement networks and groups in Ontario, food and refreshments during meetings, and a list of engagement resources related to non—health IT contexts. The full list of forced sort rankings is available in Table 4.

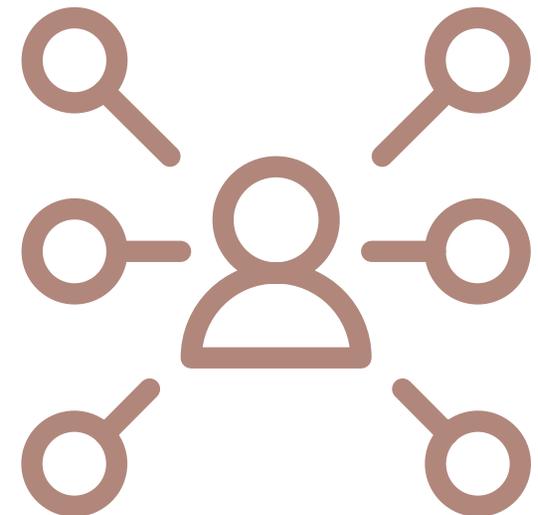


Table 4
Forced sorts means for all 30 items ranked.*

Rankings between			
5.00 and 4.00	3.99 and 3.00	2.99 and 2.00	1.99 and 1.00
Recognition of power dynamics (4.60)	Creation and sustainment of patient and family advisory council (3.83)	Engagement in HIT selection (2.83)	List of Ontario patient and family engagement network groups (1.83)
Governance structures (4.17)	Using multiple types of engagement (3.67)	List of different HIT engagement methods (2.67)	Literature review describing benefits of patient and family engagement in HIT (1.83)
Engagement in HIT evaluation (4.00)	Engagement in HIT use and adoption (3.33)	Guiding principles for patient and family HIT engagement (2.67)	Food and refreshments during meetings (1.33)
Engagement in requirements-gathering processes (4.00)	Non-HIT-specific engagement principles (3.17)	Honorariums or payment for time and expertise (2.50)	List of non-HIT-related patient and family engagement resources (1.17)
Engagement training for health care staff (4.00)	Engagement in short- and long-term HIT strategy (3.00)	Meetings scheduled after 9-to-5 work hours (2.50)	
Patient and family HIT training (4.00)	Formal recognition of participants' efforts (3.00)	Suggestions for choosing engagement methods for health care organizations (2.50)	
	HIT usability testing (3.00)	Suggestions for how to chair and conduct meetings with patients and family members (2.50)	
	Onboarding and orientation of participants to health care organization (3.00)	Suggested patient and family member recruitment strategies (2.17)	
	Transportation, parking and mileage allowance for participants (3.00)	Communication skills training (2.00)	
		Engagement in HIT procurement (2.00)	

* When rankings are identical, items are displayed in alphabetical order.

Knowledge translation strategies

Symposium participants identified several knowledge translation strategies, which fall under the following themes: (1) endorsements, (2) education and (3) marketing/communication (see Table 5). Participants identified endorsements from large, prominent and

respected organizations or associations as being important to support the future resource document. Many participants discussed the need for education on health IT, and for engagement, that encompass the needs of patients and family members as well as of professional staff. This education could be part of training, be incorporated into relevant professional and postgraduate curricula,

or be part of hospital-wide education. A combination of indirect and direct marketing and communication was suggested to raise awareness of engagement practices and strategies.

Formatting and structure of the resource document

Participants identified desired aspects of the proposed resource document, which can be organized into five overall themes: (1) ease of access, (2) ease of use, (3) content, (4) maintaining currency and relevance and (5) audience-specific information (see Table 6). Participants recognized that the future resource document should be accessible to a wide range of audiences with different literacy levels, home languages and abilities, and should be available in various mediums, including being accessible for free on a website. To ensure that the proposed resource document stays relevant and current, it was suggested that it should be a live document that is dynamically evolving and open to feedback from its users. Furthermore, participants articulated that the strategies presented in the document should be adaptable to the variable range of funding and resources that its users may have available.

Table 5 Knowledge translation strategies: Themes with definitions

Endorsements: The future resource document could be endorsed by large research hospitals, respected health organizations, professional associations, health IT conferences, digital health organizations, and patient and family advocacy groups.

Education: Educational materials should be implemented organization-wide in the form of training programs for both patients / family members and staff. Engagement practices can be incorporated into the curricula of graduate health informatics programs, and health care organizations can create certification programs in patient and family engagement.

Marketing and communication: The proposed resource document should be marketed using a combination of direct and indirect marketing and communication methods. Advertisements could use various mediums to reach the potential target audience, and should run in various locations.

Table 6

Specifications for the proposed resource document: Themes with definitions

Ease of access: The proposed resource document should conform to accessibility standards, be available in multiple languages, be accessible to the public (i.e., free online) and be available in multiple mediums (e.g., written, verbal, video module).

Ease of use: The resource document should include instructions on its use, be easily comprehensible regardless of literacy level, and be visually appealing and concise.

Content: When referring to stakeholders, the document should use language and titles chosen by stakeholders themselves. It should also include people's lived experiences with health IT engagement, and feature terms of use, an index, references and a glossary.

Maintaining currency and relevance: The document should be a living document that is regularly updated, and should include the capacity for its users to provide feedback. Feedback collection should have a specific plan and objective.

Audience-specific information: The document's recommendations and tips should be adaptable to the varying resources and funding that users may have at their disposal. It should be relevant to a variety of health contexts and disciplines.

Section 4

Considerations and recommendations

In this section, we synthesize and consolidate the considerations and strategies for engagement that were collected in the research activities described in Section 2. These considerations and recommendations can inform the content and presentation of the proposed resource document.

Content recommendations

The recommendations on content are presented in the following sequence: (1) preparation, (2) execution and (3) evaluation.

1. Preparation

Various potential enablers and barriers should be considered in preparing for the engagement of patients and families. Seven guidance documents highlighted the key enablers and barriers that organizations should consider in creating an organizational culture

that supports partnerships and collaboration with patients and their families (see Table 7).

Table 7
Enablers of and barriers to engagement^{59,62,64,66,73,75}

Enablers	Barriers
Engagement is a strategic priority with allocated resources	Resources (time and budget) are limited
There is genuine buy-in from executive and management-level staff	Patients and family members are not reimbursed, and/or cannot participate because assistance they require is not provided
There is genuine commitment to partnerships to improve health services	Senior health professionals are not given adequate non-clinical time to manage, develop and support engagement
Standardized processes are established to support engagement	There is a fear of change and accountability
Documentation and evaluation is taking place	

Table 7 continued

Enablers	Barriers
There is training for both patients and staff to prepare patients to be partners and active team members	There is a lack of understanding of the benefits of engagement
The mechanisms for consumers and community members to bring ideas to the organization are communicated effectively	There is division between clinical staff and stakeholders
There is ongoing commitment from health care organizations and staff to solicit and utilize the experiences and perspectives of patients and caregivers	There are no policies or procedures in place to support training initiatives
Patients are offered the opportunity to learn about their health care and about health policy through simple, easy-to-understand information	There is only a single patient or family member on a steering committee
Health care organizations and professionals recognize and act upon their responsibility to engage social groups that are disadvantaged and marginalized	Orientation, training or professional development is not provided
Proper evaluation of patient engagement processes and outputs allows initiatives to show value and areas for improvement	Executives and management do not provide leadership and support
Supportive structures (e.g., policies, processes) are created that embed and enable patient engagement	Engagement is not an organizational priority
Patients are assured that their privacy is protected	Patients and health professionals lack knowledge and experience in patient engagement
	Patients lack confidence in the health care organization
	Health professionals are considered the experts and patients defer to the guidance of the professionals
	Engaged patients may not adequately represent the populations served by the health care organization

An engagement plan may be a useful tool to inform the overall execution of engagement activities. In preparing for engagement activities, it is important to consider and plan for considerations such as how individuals will be recruited, when they will be involved, and what incentives might be necessary to encourage sustained participation (see Table 8).

Results from both the literature review and the focus groups demonstrate that considering timing, financial barriers and accommodations for accessibility prior to engaging can help enable patients and their families to meaningfully contribute to the project. Potential barriers should be identified and addressed during this preparation phase.

Table 8
Considerations and recommendations noted by guidance documents for planning engagement activities^{1,6,57-75}

Recruitment for engagement
Partner with patient organizations and external agencies to provide knowledge and useful contacts
Engage and develop relationships with local community or social service organizations to recruit patients and family members from specific populations
When engaging external organizations with public interest, contact the organization through a known colleague
Engage an experienced patient champion or patient engagement specialist who can recruit and train additional patient partners and set up patient advisory councils
Advertise projects in local newspapers and on social media such as Facebook or Twitter
Prioritize engaging marginalized populations, with a focus on people who are racialized, have a low income, are disabled, and/or are part of a range of culturally and linguistically diverse backgrounds

Table 8 continued

Location of engagement

Meet patients and families in their own environments and ensure that meeting places are accessible to all

Timing of engagement

Involve people as early as possible in the process, so they feel part of the project and have a sense of ownership

Engage stakeholders at the planning phase to maximize their opportunity to contribute and shape the outcome

Organize meetings and workshops at appropriate times to make participation as practical as possible

Ensure that engagement takes place across multiple phases, such as during the planning, implementation, monitoring and evaluation of projects

Consider the length of meetings, and include lots of breaks to avoid overburdening patients and families

Incentives for engagement

Encourage participation by outlining outcome measures that are relevant to patients

Allocate budget to reimburse participants for expenses (e.g., time, travel, training, translation, attendance of conferences or other events)

Enable patients to be involved by providing child care, elder care, parking and accommodation

2. Execution

Stakeholder engagement can be described from a variety of perspectives, with one example being how involved the patient or family member becomes in the overall decision-making process (see Table 9). However, increasing engagement and empowerment is not the only focus: how patients and families are involved relates to the overall goal that is agreed upon by all stakeholders (see Table 3). The engagement team and the engaged population need to discuss,

clarify and document the roles, responsibilities and scope of the overall engagement initiative.^{40,42,44,45,47} In these discussions, the level of engagement that meets patient/family and organizational goals can be agreed upon. Additional discussions should establish stakeholders' proposed time commitment and suitable methods of engagement. A timeline should be agreed upon that delineates the method and frequency of periodic follow-up communication (e.g., emails, phone calls, online meetings) that would begin once the engagement period was over. Patients and family members should be made aware that, at these points of follow-up communication, they will be updated on the progress or results of the project and how their feedback, ideas or input have been incorporated.

The International Association for Public Participation (IAP2) has developed a Participation Spectrum to help organizations select activities that are appropriate to the level of participation that defines the stakeholder's role in the engagement process (see Table 9).²⁸ This spectrum is used by numerous health care organizations and government agencies to guide their engagement strategy.

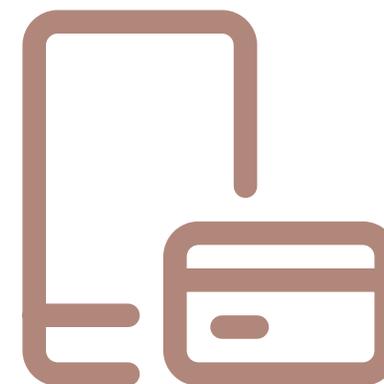


Table 9
Types of engagement activities

IAP2 participation spectrum task ²⁸	Engagement methods ^{60,61,63,70,73}
Inform	Pamphlets and fact sheets, websites, expos and fairs, telephone hotline, open house, dialogue circles, town halls, mail-outs, press releases, brochures, newsletters, local newspapers, minority language media, public education forum
Consult	Focus groups, surveys, public meetings, polling, patient forums, online discussion groups, conferences, World Cafés
Involve	Public advisory groups, working groups, workshops, interviews
Collaborate	Planning workshops, citizen advisory committees, retreat, World Cafés, participatory decision making, consensus building
Empower	Citizen juries, think tanks, study groups, task forces, panels, citizen juries, ballots

There may be a need to support patients and families during the engagement process; various approaches to this were identified in the literature review. They include:

- supporting patients in sharing responsibility for engaging under-represented groups and mentoring other patients¹
- providing formal or informal training and support so patients and families can carry out their role effectively^{61–64,75}
- training staff and patients/families on how to partner and communicate effectively with each other⁶⁴
- implementing policies and procedures to guide transparent processes that support staff in creating meaningful and equal partnerships with patients and families^{64,74}
- providing patients with opportunities for professional development outside of engagement activities (e.g., attending

- conferences or professional workshops)⁶⁴
- providing information before meetings (e.g., via a telephone call) to talk through the format of the meeting⁷¹
- providing patients with background materials or readings to prepare for meetings, given that they may not be subject matter experts⁶⁵
- ensuring that language translation services are available if needed.⁷²

3. Evaluation

After the engagement period, an evaluation can be done to identify the strengths and weaknesses of the engagement efforts, flag areas for improvement, and provide accountability for all stakeholders involved in the engagement process.⁶⁵ The evaluation of engagement activities can be built into project plans⁶⁴ and can take place in a variety of ways:

- provision of evaluation forms or surveys to be completed anonymously⁷¹
- evaluation of activities through discussion with patients and families⁶⁵
- leveraging existing standardized tools to assess the planning, execution and impact of engagement.⁶⁵

An example of an existing standardized tool to measure the quality and impact of engagement is the Public and Patient Engagement Evaluation Tool (PPEET), designed by the Centre of Excellence on Partnership with Patients and the Public.⁷⁶ In addition to evaluation methods, guidance documents encourage the use of performance measures and specific objectives to quantify and compare the value of engagement initiatives between various projects.⁶¹ There are a variety of measures that the engagement team can collect and measure to evaluate their engagement initiatives (see Table 10).

Table 10
Sample process and outcome measures that can be collected by engagement teams⁷⁴

Engagement process measures	Engagement outcome measures
Level of patient and/or family member representation	Overall satisfaction with engagement activities
Patient, family and project team satisfaction	Clinical/patient outcome improvements (if relevant)
Rate of participation	How well stakeholders are heard and understood
Level of timeliness	Number of engagement goals or objectives achieved
Level of diversity in opinions and experiences	Level of trust between various parties
Existence of clearly defined tasks and responsibilities	Impact of physical environment on engagement
Level of transparency (from organization)	Level of knowledge or information obtained

It is important to document any suggestions or lessons learned, to improve future projects and share with others. As part of the evaluation plan, engagement teams can send a report externally, providing patients with feedback on the impact of their input and any constraints that may have hindered the implementation of their recommendations. By evaluating engagement activities, project teams can determine if engaging individuals in making recommendations or implementing changes is valuable, and if re-engagement is necessary.

Recommendations on presentation

During the symposium there were many suggestions on how the content of the proposed resource document should be presented. These suggestions have been summarized and elaborated in this section.

Participants recommended that the proposed resource document be made available in the public domain, conform to web-accessibility standards, and be available in multiple languages. Because the aim of the document may be to broadly inform health IT engagement practices for patients and family members, these stakeholders make up part of this audience—and so the resource should be accessible to anyone, regardless of their location, knowledge of health IT, or literacy level. Along with these requirements, the resource document should include instructions on its use and be written succinctly using plain language. For the document to continue to be useful, its currency and relevance would need to be maintained. Consequently, it must be a living document that can be revisited and updated regularly. The document owners should also have a process for users to provide feedback, with specific guidelines and objectives for obtaining feedback. During its creation, a plan should be made to assign ownership of the document to an organization responsible for managing feedback, and for periodically updating it.

The resource document should include information that is relevant to various health care contexts and disciplines with access to varying amounts of funding, available time and other resources. Participants at the symposium suggested that this might be achieved by, for example, structuring the resource document according to health care context and amount of available resources, or creating different versions of the document targeted to specific

audiences. The resource document should also be created with awareness that its users may have varying comfort levels with technology.

Lessons learned

In addition to the research findings, several lessons were learned from the research team's methodology for engaging patients and families, from the planning stage to the implementation of research activities.

Value of experienced participants

The research team found that it was valuable for participants in the described activities to have prior experience with engagement projects. Those with previous experience of engaging in any sort of health project (not necessarily specific to health IT) were able to participate more productively in the focus groups and symposium activities. Experienced patient and family member representatives were also engaged as part of the planning committee for the various research activities. Their level of experience in research and knowledge translation was crucial in providing meaningful insights, and contributed to the success of a variety of items, including the search strategy for the literature review, the recruitment strategy for focus groups, and the logistics of the symposium.

Participants with limited experience in health IT, or in projects at health care organizations, required additional explanations on terminology and were not able to contribute in great detail to the development of practical strategies on engaging patients and families in specific phases of health IT projects. Nonetheless,

these participants were able to draw from their previous general experiences with the health care system to bring to light unique concerns and considerations that can be taken into account moving forward. We believe there is an opportunity for training in this respect, and that it may be valuable to provide background information on patient engagement strategies and health IT projects beforehand.

Diversity of participants

During the research project, patients and family members were involved across multiple domains and in varying capacities. We found it was helpful to recruit participants and patient partners with a diverse set of experiences. In the focus groups, participants had experiences in different areas of the health care system as patients or family members. Their range of experience allowed participants to learn from and build off one another's experiences and to develop different ideas, which were shared with the focus group facilitators.

The symposium featured a diverse group of patients, knowledge users, health professionals and other stakeholders, and this diversity of perspective and background allowed for a fruitful discussion and deliberation on the considerations needed in engaging patients and families in health IT projects.

Connection to the project

In both the focus groups and the symposium, participants said they resonated with the value and overall purpose of the research project. We found that participants' level of connection with the project's purpose and objective enhanced their willingness to

meaningfully participate and contribute. Similarly, knowledge users from other health care organizations were encouraged to participate actively by the value they saw in the development of a resource document.

We found too that the reciprocal aspect of engagement is important: engagement should not just be for the sake of obtaining stakeholders' approval on a project, which would be tokenistic and would discourage them from participating in future engagement efforts. Conversely, participants felt connected to the project and its impact when the research team acknowledged their feedback, allowing participants to see that their input made a difference. We learned that by communicating the value of the project explicitly, and responding readily to participants' feedback, participants felt connected to the project and thus were willing to participate.

Specific lessons learned from symposium activities

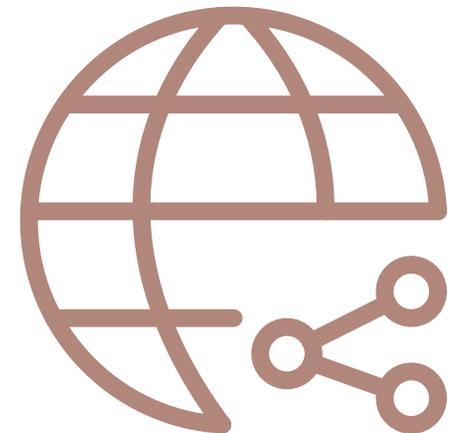
Feedback on the symposium was overwhelmingly positive. Participants were satisfied with the day and time, venue and structure of the event. Participants found that the diverse activities of the symposium were an effective way to gather data and a great opportunity to voice their opinions. Feedback indicated that more specific definitions of terms involved in the group priority sort would have been helpful to level out differences in familiarity with health IT vocabulary.

Section 5

Future directions

With the information and findings outlined in this report, the next step is to develop the proposed resource document itself. Potential partners and allies that can be leveraged in developing this document are national organizations with experience working with various health care organizations and producing useful tools to support Canadian health care. A marketing and communication strategy will also need to be developed. This strategy will guide how the resource document will be disseminated to health care organizations across Canada, and outline relevant partners and organizations that can be leveraged in increasing awareness of the document.

Another outstanding issue is whether the published resource document will be a living document that is continually edited and updated. The research team, project partners and relevant stakeholders need to resolve this issue and identify individuals who would assume the responsibility for maintaining and updating the living document.



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