McMaster University | Health Forum

Rapid Synthesis

Examining the use and implementation of real-time patient feedback programs

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Context

- Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) are standardized survey instruments that collect and measure patients' self-reported care experiences and health outcomes, respectively.
- Real-time feedback initiatives collect data during a patient's admission to a health facility or shortly after discharge and may also be referred to as near real-time feedback initiatives.
- These initiatives may have the potential to improve patient safety and outcomes, increase shared decision-making, and inform professional, organizational, and policy learning to improve health systems.
- These initiatives can vary greatly in relation to the sector in which they are implemented, how and when feedback is collected, and by whom and for what purpose it is used.
- Taking stock of the definitions, features and impacts of real-time patient feedback initiatives, as well as their barriers and facilitators to implementation, can help inform policymakers' efforts to develop future real-time patient feedback approaches.

Box 1: Evidence and other types of information

+ Global evidence drawn upon

Evidence syntheses selected based on relevance, quality, and recency of search

+ Forms of domestic evidence used (🍁 = Canadian)

Evaluation

Qualitative insights

+ Other types of information used

Jurisdictional scan (six countries: AU, CA, IT, NZ, US, UK)

*** Additional notable features**

Prepared in thirty business days

Question

- What are the definitions, features, and impacts of real-time patient feedback programs (PREMs and PROMS), and how do they compare to non-real-time approaches?
- How are real-time patient feedback programs being implemented, and what barriers and facilitators has their implementation faced?

High-level summary of key findings

Research evidence

- We identified eight evidence syntheses (of which we deemed six to be highly relevant to the questions) and 31 single studies (of which we deemed 17 to be highly relevant to the questions).
- Overall, most of the identified evidence focused on the implementation of real-time patient feedback programs in specialty care contexts, especially in outpatient settings, with only two studies also including home care and one study focusing on primary care.

- The most common areas of specialty care included cancer care, various types of surgeries, urological conditions, and palliative care.
- The ways in which real-time patient feedback initiatives are implemented vary considerably, highlighting the importance of fit-for-purpose approaches.
- Real-time patient feedback initiatives have the potential to enhance patient monitoring and care decisions, increase patient involvement, and advance professional learning.
- However, the lack of evidence comparing real-time with non-real-time approaches limits the extent to which inferences can be made about for which patients and under what circumstances real-time feedback may be more or less useful.
- Compared to paper-based methods, electronic patient-feedback initiatives appear to be more efficient and provide more accurate data.
- Key barriers include financial, human, and time costs associated with developing necessary infrastructure, while key success factors include team collaboration, ongoing support, integration with existing workflows, and user-friendly systems.

Jurisdictional scan

- Across Canada and five other countries we examined (Australia, Italy, New Zealand, U.K., U.S.), real-time patient feedback initiatives have largely been implemented in specialty care settings, such as for surgery and cancer patients.
- Many of these initiatives aim to integrate real-time patient feedback with broader electronic health record or health data systems, enhancing care-related decision-making and enabling service evaluation and benchmarking.
- Some interoperable systems and digital platforms have been used to automate feedback collection, make it accessible in real-time for clinicians, healthcare managers, and patients, and in some cases provide rapid guidance or communication with health providers if intervention is necessary. Key implementation considerations beyond those identified in the evidence include ongoing staff and volunteer training, and a culture of continuous improvement within the organization implementing the initiative.

Box 2: Approach and supporting materials

We engaged two citizen partners who reviewed the scope and question and ensured relevant context is taken into account in the summary of the evidence. Feedback provided by the citizen partners has been incorporated into the report.

We identified evidence addressing the question by searching Health Systems Evidence and PubMed to identify evidence syntheses, protocols for evidence syntheses, and primary studies. All searches were conducted on 15 July 2024. The search strategies used are included in Appendix 1. We identified jurisdictional experiences by hand searching government and stakeholder websites for information relevant to the question from five countries including Australia, Italy, New Zealand, U.K., and U.S., as well as all Canadian provinces and territories.

In contrast to our rapid evidence profiles, which provides an overview and insights from relevant documents, this rapid synthesis provides an in-depth understanding of the evidence.

We appraised the methodological quality of evidence syntheses that were deemed to be highly relevant using the first version of the AMSTAR tool. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. The AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to evidence syntheses pertaining to delivery, financial or governance arrangements within health systems or implementation strategies.

This rapid synthesis was prepared in a 30 business day timeline.

A separate appendix document includes:
1) methodological details (Appendix 1)
2) key findings from included evidence syntheses and primary studies (Appendix 2)
3) details about each identified synthesis (Appendix 3)
4) details about each identified single study (Appendix 4)
5) details from the jurisdictional scan (Appendix 5)
6) documents that were excluded in the final stages of review (Appendix 6)
7) references (Appendix 7).

Framework to organize what we looked for

- What real-time feedback is collected?
  - Patient-reported experience measures
  - Patient-reported outcome measures
    - Generic
    - Condition-specific
- For which sectors is real-time feedback collected?
  - Home and community care
  - Primary care
  - Speciality care
    - Hospital inpatient
    - Surgical services
  - Rehabilitation care
  - Long-term care
  - Public health
- When is real-time feedback collected?
  - During a clinical encounter
  - Immediately following a clinical encounter
  - Hours or days following a clinical encounter
  - Multiple times
- What methodological approach is used to collect feedback?
  - Self-reported survey
  - Interview with healthcare staff
- How is feedback collected?
  - Patient portals
  - Paper and pen
  - Healthcare clinic or hospital technology (e.g., computers, tablets)
  - Patient's own technology (e.g., computers, tablets, smartphones)
- By whom is real-time feedback used?
  - Patients and clinicians
  - Organizational leaders
  - Policymakers and system planners
  - Researchers
- For what purpose is real-time feedback collected?
  - To increase patient involvement in decision-making
  - To inform care decisions
  - To inform learning and improvement at the professional level
  - To inform learning and improvement at the organizational level
  - To inform learning and improvement at the system level
  - To inform health services planning at the organizational level
  - To inform health services planning at the system level
  - To support research efforts
- What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  - Health outcomes
  - Patient experience
  - Provider experience
  - Costs
- Implementation of real-time feedback programs

- Barriers to implementation
- Facilitators to implementation

What we found

We identified 39 evidence documents (eight evidence syntheses and 31 single studies) relevant to the question, of which 23 were deemed to be highly relevant (six evidence syntheses and 17 single studies). The highly relevant evidence documents include the following six evidence syntheses (one high quality, three medium quality, and two low quality):

- A review of the barriers to using Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs) in routine cancer care (AMSTAR rating 2/9; search last conducted 2019)
- Improving the understanding and managing of the quality of life of patients with lung cancer with electronic patient-reported outcome measures: Scoping review (AMSTAR rating 2/9; search last conducted 2022)
- Electronic symptom monitoring for home-based palliative care: A systematic review (AMSTAR rating 9/11; search last conducted 2023)
- Near real-time patient experience feedback with data relay to providers: A systematic review of its effectiveness (AMSTAR rating 7/9; search last conducted 2023)
- Assessing patient-reported outcomes in routine cancer clinical care using electronic administration and telehealth technologies: Realist synthesis of potential mechanisms for improving health outcomes (AMSTAR rating 6/9; published 2023)
- Evaluating digital maturity and patient acceptability of real-time patient experience feedback systems: Systematic review (AMSTAR rating 5/9; search last conducted 2017)

We outline in narrative form below our key findings related to the questions from highly relevant evidence documents and based on experiences from the jurisdictional scan of five countries (Australia, Italy, New Zealand, United Kingdom and the United States) and all Canadian provinces and territories (see Box 1 for more details).

A summary of the evidence organized by sector is provided in Appendix 2, while a summary of the experiences from other countries and from Canadian provinces and territories is provided in Appendix 5. Detailed data extractions from each of the included evidence documents is provided in Appendices 3 and 4, and hyperlinks for documents excluded at the final stage of reviewing in Appendix 6.

Key findings from highly relevant evidence sources

Q1: What are the definitions, features, and impacts of real-time patient feedback programs (PREMs and PROMS), and how do they compare to non-real-time approaches?

Overall, most of the identified evidence focused on the implementation of real-time patient feedback programs in specialty care contexts, especially in outpatient settings. The most common areas of specialty care included cancer care, various types of surgeries, urological conditions, and palliative care. Fewer programs appear to have been implemented and studied in other sectors, with only two highly relevant studies bridging the specialty care and home care sectors (1; 2) and two focused on primary care.(3; 4) The programs most often leveraged self-reported surveys that were collected through the patient's own technology (e.g., computer, tablet, smartphone) or healthcare clinic or hospital technology (e.g., computers, tablets). Feedback was most often collected multiple times (generally as a way of monitoring patient-reported outcomes (PROs) and informing intervention or changes to care) or during a clinical encounter. The feedback was most often used by patients and clinicians to inform care decisions, increase patient involvement in decision-making, and inform learning and improvement at the professional and organizational levels. The most assessed outcomes were related to patient experience, health outcomes, provider experience, and costs. Real-time patient feedback was often not defined explicitly in studies, and the ways in which this type of feedback was collected and used tended to vary across contexts. The variation in implementation makes it difficult to compare or aggregate outcomes across studies.

Specialty care – hospital inpatients

Real-time patient feedback collected during clinical encounters in hospitals generally focused on PREMs. A medium-quality systematic review in which most of the included studies were conducted in hospitals found that real-time feedback approaches using digital technology generally used touchscreens, tablets, and web-based platforms, and showed promise among healthcare staff for reducing fatigue. The approaches were generally acceptable to patients, although patient characteristics such as gender, age and ethnicity may influence response rates and organizations' existing digital infrastructure can greatly influence the extent to which such approaches can be successful.(3) An Italian case series study of 21 hospitals adopting electronically collected PREMs found that the program allowed for the monitoring of care assistants' contribution to the positive experience of patients, which had previously been difficult to measure.(5) A prospective observational study found that the implementation of a near real-time patient experience approach in a hospital cancer centre is feasible, with high participation rates (at least some responses) (79%) and completion rates (all responses completed) (67%).(6) Although almost all studies we identified focused on self-reported surveys, a medium-quality systematic review found that in-person interviews used to collect real-time feedback in hospitals resulted in significantly more favourable outcomes in patient experience measures, and that kiosk-based near real-time feedback did not lead to improved patient experience results.(7)

Specialty care – outpatient monitoring

Speciality care models using real-time patient-reported feedback for monitoring and intervention generally collected data on PROs. Two evidence syntheses focusing on palliative home care, for example, examined the use of electronic patient-reported outcome measures (ePROMs) to improve patient symptom reporting. A low-quality scoping review included programs using real-time ePROMs and found that they were an effective way to maintain communication between healthcare providers and patients with lung cancer in palliative home care, while improving patient quality of life and access to symptom management information and care.(1) Similarly, a high-quality systematic review found that the implementation of PROMs is a cost-effective method for measuring real-time symptoms and can contribute to an improvement in quality health care, patient autonomy, and quality of life for patients in palliative homecare.(2)

Similar approaches have been implemented to monitor cancer patients. A low-quality review found that using real-time PROMs in clinical oncology improved patient participation in treatment, communication between healthcare providers, and patient quality of life.(8) A medium-quality realist synthesis found that ePROMs can improve proactive management of symptoms, communication between healthcare workers and patients, and facilitate decision making.(9) In one randomized controlled trial, a weekly real-time electronic patient-reported outcome symptom questionnaire and real-time advice system was found to improve physical well-being (six to 12 weeks) and self-efficacy (18 weeks) in cancer patients without increasing hospital workload.(10) A feasibility study of electronic patient-reported outcomes (ePROs) at a Kaiser Permanente oncology centre found that ePROs were beneficial for patient care and symptom management when properly integrated into local workflows and supported through team collaboration.(11) Similarly, six other studies evaluating approaches that routinely collect patient-reported health-related quality of life in cancer patients found that these approaches were feasible, had high compliance, and have the potential to improve symptom control, but rarely led to physicians changing provided care.(12-17) A survey study found that the implementation of an online portal for collecting ePROs in patients with cancer before hospital visits found that the approach was feasible(18), and a pilot study of an ePROM approach for post-radiation therapy care was found to be feasible while streamlining follow-up appointment scheduling.(19)

Finally, two other studies focused on real-time PROMs to monitor patients with urologic conditions. In a feasibility study capturing PROMs in older adults with end-stage renal disease on hemodialysis using an iPad-based electronic tool, the program was found to be an efficient and easy-to-use method to monitor patient symptom burden and quality of life.(20) A cross-sectional survey study found that PROMs using automated text messaging in urologic surgery patients has the potential to support healthcare and policy decision-making in forming guidelines for best practice.(21)

Primary care

Only two studies focused on the implementation of a real-time feedback program in a primary care context. A mixed-methods study on the implementation of an electronic patient-reported outcome system into routine primary care at a primary health centre found that the system increased completion rates of health assessments, identified critical health issues, reduced paperwork for staff, and was well-received by both patients and providers for improving communication and care efficiency.(4) A medium-quality systematic review that included some studies in primary care settings found that real-time approaches in these settings often used tablets and kiosks, and while response rates varied considerably across studies, they were generally lower than response rates in studies conducted in hospitals.(3)

Real-time versus non-real-time approaches

Few studies explicitly evaluated real-time patient-reported feedback approaches compared to non-real time paper-based methods, although many of the feasibility/pilot studies appeared to be transitioning to electronic/real-time approaches from non-real time/paper-based ones. One study that did explicitly compare the two approaches was a feasibility pilot study carried out through a randomized controlled trial, and found that a web-based platform for collecting electronic PROMs in child and adolescent mental health services are less time-consuming, require less administrative effort, cost less, and produce more accurate responses compared to paper-based methods.(22) Another study of an approach collecting daily micro-surveys of patient reported health-related quality of life using smartphones among patients recovering from cancer surgery found that it was feasible and has the potential to reduce human, time and financial resource costs compared to paper-based methods.(17)

Q2: How are real-time patient feedback programs being implemented, and what barriers and facilitators has their implementation faced?

Studies frequently highlighted a range of barriers and facilitators supporting real-time patient feedback programs. Key barriers included:

- lack of infrastructure such as poor internet or access to electronic devices (1; 14)
- initial costs such as for hardware and software to collect and integrate data, as well as maintain patient privacy (1; 23)
- limited staff engagement and potential overburden.(4; 6; 14; 16; 23)

Key facilitators included:

- relationship building, team collaboration, and ongoing implementation support (6; 11)
- physician champion (18)
- training clinical staff on the real-time feedback approach (8; 18)
- integrating and optimizing the approach based on existing workflows (11; 16)
- ensuring the feedback collection process is easily accessible and user friendly (8; 9; 11)
- customizing systems and tailoring the feedback questions to patients (9; 23)
- efficient responses to feedback that are actionable (9)
- integration with electronic health records.(4; 8)

Key findings from jurisdictional scans

Given that the jurisdictional scan was focused on identifying experiences from Canada and other countries, it was most relevant for question 2 for this rapid synthesis (How are real-time patient feedback programs being implemented, and what

barriers and facilitators has their implementation faced?). As a result, the findings below do not address question 1. Additionally, where few or no real-time patient feedback initiatives were identified, we also searched for other electronic patient feedback approaches that could be seen as laying the foundation for or moving towards real-time feedback approaches. We have therefore separated the jurisdictional scan findings into two sections to separate their findings.

Real-time patient feedback approaches

In Canada, efforts to integrate real-time patient feedback approaches into electronic medical records (EMRs) have been emerging at national and provincial levels. At the pan-Canadian level, the Canadian Institute for Health Information provided guidance for integrating electronic, real-time PROMs for hip and knee arthroplasty. Additionally, initiatives in Ontario (email surveys sent two days after appointment), and Manitoba (point-of-care paper-based surveys entered into CancerCare Manitoba EMRs), aim to collect PREMs and PROMs specific to cancer patients to inform care. In B.C., some efforts have been made to coordinate the collection of real-time patient feedback across settings. The Fraser Health Authority partnered with their Regional Patient Advisory Council (PAC) to develop a quick electronic survey for patients to complete during care about their experience, enabling managers to access real-time data 24/7 at the unit level. Patients reported feeling their feedback is valued and appreciated the opportunity to help improve services. Finally, two initiatives in Nova Scotia and New Brunswick leverage applications that help connect patients recovering from cardiac surgery and receiving radiotherapy, respectively, to monitor symptoms through PROs and plan care accordingly.

Internationally, the countries we scanned have undertaken a variety of national, regional, condition-specific, and organizational real-time and electronic patient feedback initiatives. In the U.S., several initiatives aimed to scale-up real-time electronic patient feedback (PROs) and integrate this feedback into electronic health records to help inform care decisions, support shared decision-making, advance research efforts and inform learning and improvement efforts at unit, organization, state, and national levels. These initiatives were often designed to be flexible and did not specify when the patient feedback was being collected. However, from examples given, it was clear that at least some of the intended applications involved collecting data during clinical encounters and some multiple times. For example, Intermountain Health, in partnership with Notable Health, developed an automated and digital platform to facilitate patient uptake and post-visit follow-up (including PROMs). The platform automatically provides patients with intelligent questionnaires after their visit to collect PROM data, which is uploaded to their electronic health records in real-time, allowing clinicians to follow a patient's trajectory and adjust care. Kaiser Permanente's feedback-informed care (FIC) for mental health care services is an approach that leverages patient-reported information (generic and mental-health specific PROs) to increase patient involvement and make clinical adjustments in real-time to reduce deterioration. As part of their efforts to modernize the HQR system, the Centers for Medicare & Medicaid Services made reports available for download in real-time, allowing immediate analysis of file accuracy and performance comparison at facility, state, and national levels.

Many initiatives have aimed to integrate patient feedback data with broader health data collection efforts or electronic health records. An initiative based in New South Wales (N.S.W.), Australia, uses an online platform called HOPE to allow for patients and providers to provide and access feedback on their experiences and outcomes, allowing for real-time understanding of services and information required by both parties. This system has operability with the N.S.W. electronic medical record and clinical systems, allowing for the analysis and summary of feedback from across multiple sources. In New Zealand, the Mārama Real-Time Feedback (Mārama RTF) initiative includes a consumer survey to provide feedback on mental health and addiction services (e.g., respect, communication, family involvement) with the intention of improving service quality and engagement. The data allowed for national comparisons across service providers.

Across the jurisdictional scans we conducted, training (e.g., how to access, interpret, and use feedback data), staffing, resources (financial or skilled support for staff), and supporting infrastructure were often highlighted as key facilitators of real-time patient feedback efforts. Other facilitators included a culture of continuous improvement within the unit or organization in which the real-time patient feedback program was being implemented. Finally, building adequate infrastructure to implement these initiatives successfully in different settings was also identified as an important consideration. For example, the U.S. Department of Health and Human Services' Office of the National Coordinator for

Health Information Technology commissioned a report on advancing PROs that highlights the need for ongoing efforts to build a comprehensive health IT ecosystem with PROs will help support PRO collection at point-of-care and use in real-time through interoperable systems.

Other electronic patient feedback approaches

In some cases, patient feedback approaches are leveraging electronic forms of data collection or integrate data into existing data systems that can provide a stronger foundation for the implementation of real-time approaches in the future. Across Canada, most of the experiences implementing electronic patient feedback has occurred in the context of specialty care, especially for hospital and surgical settings. For example, in Manitoba, provincial initiatives have been undertaken to collect PROMs for Hip and Knee Replacement Surgery, Spine Surgery, Outpatient Shoulder and Knee Surgery, and Cataract Surgery, with the goal of linking PROMs to existing health data repositories providing near real-time information to assess service quality. Implementing electronic patient feedback initiatives provides greater opportunities to utilize point-of-care and other real-time data collection approaches as well as real-time access and use of this data to help guide clinical decision-making.

Efforts to link patient feedback data to existing health data can similarly improve opportunities for real-time patient feedback initiatives by integrating patient feedback data into broader information systems that can be more readily used by clinicians and organizations to inform care and systems-level changes. For example, in the U.K., the National PROMs program focuses on assessing the quality of care delivered to NHS patients undergoing specific procedures such as hip and knee replacements. The measures evaluate health gains by comparing patients' conditions before and after surgical treatment, and are linked with Hospital Episode Statistics (HES) information. In the U.S., the Agency for Healthcare Research and Quality funded an initiative in 2018 to support standardized collection of PROs through patient electronic assessment and integration with electronic health records through mobile applications.

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