McMaster University | Health Forum

Rapid synthesis appendices

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

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Appendices

Appendix 1: Methodological details

Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes evidence drawn from existing evidence syntheses and from single research studies in areas not covered by existing evidence syntheses and/or if existing evidence syntheses are old or the science is moving fast. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select, and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

The Forum produces timely and demand-driven contextualized evidence syntheses such as this one that address pressing health and social system issues faced by decision-makers (see our website for more details and examples). This includes evidence syntheses produced within:

- days (e.g., rapid evidence profiles or living evidence profiles)
- weeks (e.g., rapid syntheses that at a minimum include a policy analysis of the best-available evidence, which can be requested in a 10-, 30-, 60-, or 90-business-day timeframe)
- months (e.g., full evidence syntheses or living evidence syntheses with updates and enhancements over time).

This rapid synthesis was prepared over a 30-business day timeframe and involved six steps:

1) submission of a question from a policymaker or stakeholder (in this case, British Columbia Ministry of Health)
2) engaging citizen partners
3) identifying, selecting, appraising, and synthesizing relevant research evidence about the question
4) conducting and synthesizing a jurisdictional scan of experiences about the question from other countries and Canadian provinces and territories
5) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence
6) finalizing the rapid synthesis based on the input of at least two merit reviewers.

Engaging subject matter experts and citizen partners

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

Identification, selection, quality appraisal and synthesis of evidence

For this rapid synthesis, we searched Health Systems Evidence (1, 2) and PubMed and for:
1) guidelines (defined as providing recommendations or other normative statements derived from an explicit process for evidence synthesis)
2) evidence syntheses
3) single studies.

In Health Systems Evidence, we searched for evidence syntheses using 'real-time,' 'patient feedback,' and 'patient-reported' terms. In PubMed, we searched for 'patient reported outcome measures' 'patient reported experience measures,' 'PROM,' 'PREM,' 'real-time,' and 'rapid.'

Each source for these documents is assigned to one team member who conducts hand searches (when a source contains a smaller number of documents) or keyword searches to identify potentially relevant documents. A final inclusion assessment is performed both by the person who did the initial screening and the lead author of the rapid synthesis, with disagreements resolved by consensus or with the input of a third reviewer on the team. The team uses a dedicated virtual channel to discuss and iteratively refine inclusion/exclusion criteria throughout the process, which provides a running list of considerations that all members can consult during the first stages of assessment.

For any included guidelines, two reviewers assess each guideline using three domains in the AGREE II tool (stakeholder involvement, rigour of development, and editorial independence). Guidelines are classified as high quality if they were scored as 60% or higher across each of these domains.

For each evidence synthesis we included, we documented the dimension of the organizing framework (see Appendix 2) with which it aligns, key findings, living status, methodological quality (using AMSTAR), last year the literature was searched (as an indicator of how recently it was conducted), availability of GRADE profile, and equity considerations using PROGRESS PLUS.

Two reviewers independently appraise the methodological quality of evidence syntheses that are deemed to be highly relevant using the first version of the AMSTAR tool. Two reviewers independently appraise each synthesis, and disagreements are resolved by consensus with a third reviewer if needed. AMSTAR rates overall methodological quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. High-quality evidence syntheses are those with scores of eight or higher out of a possible 11, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. It is important to note that the AMSTAR tool was developed to assess evidence syntheses focused on clinical interventions, so not all criteria apply to those pertaining to health-system arrangements or implementation strategies. Furthermore, we apply the AMSTAR criteria to evidence syntheses addressing all types of questions, not just those addressing questions about effectiveness, and some of these evidence syntheses addressing other types of questions are syntheses of qualitative studies. While AMSTAR does not account for some of the key attributes of syntheses of qualitative studies, such as whether and how citizens and subject-matter experts were involved, researchers' competency, and how reflexivity was approached, it remains the best general quality-assessment tool of which we're aware. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, an evidence synthesis that scores 8/8 is generally of comparable quality to another scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the evidence synthesis can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the evidence synthesis should be discarded, merely that less confidence can be placed in its findings and that it needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health

Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1): S8.)

For primary research (if included), we documented the dimension of the organizing framework with which it aligns, publication date, jurisdiction studied, methods used, a description of the sample and intervention, declarative title and key findings, and equity considerations using PROGRESS PLUS. We then used this extracted information to develop a synthesis of the key findings from the included syntheses and primary studies.

During this process we include published, pre-print and grey literature. We do not exclude documents based on the language of a document. However, we are not able to extract key findings from documents that are written in languages other than Chinese, English, French, Portuguese, or Spanish. We provide any documents that do not have content available in these languages in an appendix containing documents excluded at the final stages of reviewing. We excluded documents that did not directly address the research questions and the relevant organizing framework. All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Identifying experiences from other countries and from Canadian provinces and territories

For each rapid synthesis, we work with the requestors to collectively decide on what countries (and/or states or provinces) to examine based on the question posed. For other countries, we search relevant government and stakeholder websites including [relevant government and stakeholder websites including ministries of health, public health agencies, hospitals, primary care organizations, and other health service organizations. In Canada, a similar approach was used, which involved searching the website of government and stakeholder websites including provincial and territorial ministries of health, public health agencies, and hospitals. While we do not exclude content based on language, where information is not available in English, Chinese, French, Portuguese, or Spanish, we attempt to use site-specific translation functions or Google Translate. A full lit of websites and organizations searched is available upon request.

Appendix 2: Key findings from highly relevant evidence syntheses and single studies

Sector	Features of real-time patient feedback initiative	Outcomes	Implementation considerations
Specialty care – inpatient	• Real-time and near real-time electronic patient-reported experience measures collected through hospital technology (e.g., tablets and kiosks), either self-reported (5-7) or via in-person interviews (7)	• Implementation is feasible and has high participation and completion rates (5; 6) • In-person interviews my result in better patient experience measures compared to kiosk-based collection (7)	• Facilitator: relationship building and team collaboration (6)
Specialty care – outpatient and home care	• Real-time electronic patient-reported outcomes for palliative homecare through patients' own technology (1; 2)	• Maintains communication between healthcare providers and patients and improves access to symptom management information and care (1) • Cost-effective for measuring real-time symptoms (2) • Can help improve quality of healthcare and patient autonomy (2) • Can improve quality of life for patients in palliative homecare (1; 2)	• Barrier: lack of infrastructure (e.g., poor internet, access to electronic devices) (1)
	• Real-time electronic patient-reported outcomes for monitoring cancer patients through patients' own technology (8-19)	• Improve patient participation in treatment and communication with healthcare providers (8; 9) • Improve quality of life (8; 9) • Improvements in physical well-being and self-efficacy (10) • Improved symptom control and management (11-17; 19) • May reduce human, time, and financial resource costs associated with paper-based methods (19)	• Barriers: limited staff engagement and potential overburden (13; 15) and lack of infrastructure (13) • Facilitators: training clinical staff on the real-time feedback approach (8; 18) • Integrating and optimizing the approach based on existing workflows (11; 16) • Ensuring feedback collection process is easily accessible and user-friendly (8; 9; 11) • Customizing systems and tailoring the feedback questions to the patient (9) • Integration with electronic heath records (8)
	• Real-time patient-reported outcomes for monitoring patients with urologic conditions through patients' own technology (20; 21)	• The approach is efficient and easy to use (20)	• None identified
	• Web-based platform collecting electronic patient-reported outcomes in child and adolescent mental health services (22)	• Reduced time, costs, and administrative effort compared to paper-based methods (22)	• None identified
Primary care	• Real-time electronic patient-reported outcome system implemented into routine care at a primary care centre (4)	• Increased rates of completion for health assessments and reduced paperwork for staff (4) • Improved communication and care efficiency (4)	• Barriers: limited staff engagement and potential overburden (3) • Facilitators: integration with electronic health records (4)

Appendix 3: Key findings from evidence syntheses sorted by relevance

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
• For which sectors is real-time feedback collected?
  ○ Home and community care
  ○ Primary care
• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ 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
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
  ○ To inform learning and improvement at the organizational level
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
  ○ Provider experience
	Real-time feedback reporting to understand patient experiences and health outcomes is a feasible mode of data collection that can facilitate care decisions, given sufficient flexibility and analysis (3)
	• This systematic review evaluated patient acceptability of real-time patient experience feedback systems
	• Studies using real-time feedback in primary care or secondary care settings (not specified)
	• Feedback was mostly collected using tablets or web-based platforms, either on the patient's device or in the clinic
	• Feedback was typically used to understand patient experiences
	• Mixed results were seen in terms of response to real-time feedback
	  ○ In two studies, higher response to real-time feedback were seen in males aged 18–34
	  ○ In another study women had higher responses
	  ○ In two studies, white participants had higher responses than racialized participants
	• Patients generally reported that real-time feedback was accessible
	• Some patients expressed concerns with real-time feedback including issues with technology, lack of anonymity, and concerns of leaving feedback
	• Healthcare staff reported that real-time feedback helped reduce feedback fatigue, was most useful when neatly summarized, and could be used to inform care decision and improvements within the care centre
	• Healthcare staff noted that data should be summarized, which may require training in statistics or qualitative analysis and could be an additional burden for the team
	• Given the range of complex health conditions, flexibility in real-time feedback reporting is needed
		High	No	5/9	2017	Not available	Race/ ethnicity/ culture/ language; gender/sex

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation							

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Home and community care
• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
	The implementation of patient-reported outcome measures (PROMs) is a cost-effective method for measuring real-time symptoms and can contribute to an improvement in quality healthcare, patient autonomy, and quality of life for patients in palliative homecare (2)
	• Real-time electronic symptom monitoring in the home-based palliative care context could be a cost-effective contribution to improving quality of life and well-being for patients
	  ○ Real-time electronic monitoring of symptoms allows for patients to communicate their symptoms to their healthcare provider more easily
	  ○ Compared to face-to-face discussions, patients were more open to disclosing psychological symptoms via electronic monitoring
	  ▪ This indicates that real-time electronic monitoring of psychological symptoms could improve the psychological status of patients
	• Some patients struggled with electronic monitoring systems and found it more tedious to report their symptoms electronically
		High	No	9/11	8 September 8 2023	Not available	None

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Home and community care
• When is real-time feedback collected?
  ○ Multiple times
	Real-time electronic patient-reported outcome measures (ePROMs) are an effective way to maintain communication between healthcare workers and patients with lung cancer in palliative home care and allow for patients to have greater autonomy over their health (1)
	• In addition to improving patient quality of life and access to symptom management, ePROMs can be used on a wider systems level to inform clinical trial data and manage routine care due to their large data collection capabilities
		High	No	2/9	December 2022	Not available	None

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Patient portals
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
  ○ Researchers
• For what purpose is real-time feedback collected?
  ○ To increase patient involvement in decision-making
  ○ To inform care decisions
  ○ 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
	• ePROMs are effective as they measure the real-time symptoms and side effects a patient is experiencing rather than relying on clinical testing for treatment planning
	• There are many barriers to the implementation of ePROMs in clinical practice including the lack of infrastructure, upfront implementation costs, data concerns and resistance to change
	  ○ Lack of infrastructure refers to poor internet connectivity or access to electronic devices that allow for electronic reporting of symptoms
	  ○ Upfront costs must consider the cost of hardware and software to maintain patient privacy
	• The recent rise in telemedicine has contributed positively to the implementation of ePROM programs
	  • ePROMs are preferred over traditional paper-based patient reporting methods due to their lower cost, real-time access and higher quality data
	• ePROMs must be designed efficiently for the best use of the system. This includes having a simple and effective design that allows data to be collected as efficiently as possible
	• Patients learning to use ePROMs have reported ease when learning how to effectively report their symptoms; however, some hesitance from a small subset of patients was found
	• ePROMs have been found to be more effective at collecting data relating to a patient's psychological status compared to traditional methods						

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Specialty care
	The usage of real-time PROMs in clinical oncology should be encouraged as they improve patient participation in treatment, communication between healthcare providers and the patient, and quality of life; however, barriers at the patient level, health practitioner level, and service level are present that must first be addressed to effectively implement PROMs (8)
	• Patient-level barriers include the long survey completion times, which add to patient burdens when undergoing treatment; a solution to this barrier is to simplify PROMs to
		High	No	2/9	September 2019	Not available	None

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Patient portals
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To increase patient involvement in decision-making
  ○ To inform care decisions
• 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
	include only the most necessary and straightforward questions.
	  ○ Some patients perceived questionnaires to be irrelevant to their condition; more straightforward questions and an explanation about the usage of the PROMs may aid in reducing this barrier
	• Additional patient-level barriers included challenges answering questions on the questionnaires due to lack of understanding of the question or remembering symptoms
	  ○ One suggested solution to this barrier is the use of a proxy to aid in the completion of the PROM questionnaires, especially for those who have limited skills working with technology
	• One major reported health professional (HP) level barrier to the successful implementation of PROMs into clinical practice is the time required to monitor and engage with real-time questionnaires
	  ○ However, it is suggested that monitoring PROMs compares similarly in time to clinical interaction times and may save additional time when a patient visits the clinic as the HP will already have patient-reported outcome (PRO) data available to them
	• HPs must be trained to effectively interpret PRO data; furthermore, they must be trained on the technology used by the PROMs to use the data effectively
	• PROM questionnaires must be improved to develop actionable thresholds for symptoms to allow HPs to guide healthcare decisions more effectively
	• PROMs should be easily accessible on patient devices and available on the patient's own time in order to address service level barriers
	• PRO data must be integrated into electronic medical records in order for care decisions to be made effectively						

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
• For which sectors is real-time feedback collected?
	Given sufficient adherence and patient tailoring, real-time electronic patient-reported outcome measures (ePROMs) can improve proactive management of symptoms, communication between healthcare workers and patients, and facilitate decision making (9)
	• This review looked at the mechanisms related to the effectiveness of ePROM
		High	No	6/9	Published 2023	Not available	None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
○ Specialty care • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	• This review concluded that real-time feedback prompts can help patients learn to proactively manage their symptoms and facilitate communication with healthcare professionals ○ Given that real-time feedback can occur anywhere, patients can report their symptoms in the comfort of their own home, when they are more relaxed ○ Real-time feedback can help minimize recall bias ○ Prompt symptom identification helps avoid delayed symptom management ○ Frequent reporting helps participants improve at identifying their symptoms ○ ePROMS can facilitate communication and help patients have better experiences by feeling more cared for • Facilitators to implementation included: ○ strong patient engagement ○ efficient clinician response to feedback helps demonstrate the utility of the platform to patients ○ user-friendly platforms ○ self-reliant patients might be more practiced and engaged with ePROMS ○ time trends and graphical displays of symptoms over time can facilitate clinician use of ePROMS for care decisions ○ outcomes that are tailored and relevant to patients ○ feedback that is meaningful and actionable • Individuals with fluctuating symptoms, high symptom burden, or who are at risk for developing a condition may be more likely to adhere to ePROMS • A possible negative impact of this intervention is that ePROMs might be a constant reminder of patient illness and increase burden ○ For people with chronic health issues and symptoms, ePROMS can be particularly burdensome • Although those with low digital literacy may initially struggle with this program, efforts can be made to educate these groups and provide them with needed accessibility supports						
• What real-time feedback is collected? ○ Patient-reported experience measures	In-person near real-time feedback (NRTF), whether it involved patient-specific data or aggregated and peer-compared data, resulted in significantly more favourable outcomes in all or some patient experience measures; in contrast, a kiosk-based, actively	High	No	9/11	2023	Not available	None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospital inpatient
  ▪ Surgical services
• When is real-time feedback collected?
  ○ During a clinical encounter
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
  ○ Interview with healthcare staff
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
  ○ To inform health services planning at the organizational level
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
	self-reported NRTF – followed by aggregated data relay – did not lead to improved patient experience results (7)
	• Reviewed literature on the impact of the use of NRTF, coupled with data relay to providers on standardised self-reported patient experience measures
	• In total eight studies were included consisting of three randomized controlled trials (RCTs), one non-randomized QI trial, and four pre-post-test studies
	• Nimbler NRTF surveys can facilitate change; however, the NRTF must be meaningful for the patient, as their recollection of being rounded on (rather than the mere fact of being rounded on) significantly increases the likelihood of them providing top patient experience scores
	• Kiosk-based approaches typically generate low response rates (e.g. 2.5% for kiosk-based touch screens installed in healthcare facilities' waiting areas) and patients aged above 65 were underrepresented
	• In-person rounding on patient experience can offer greater opportunities for relationship building compared to completing a questionnaire
	• In-person rounding process, when conducted with empathy (rather than as a "box-ticking" exercise), can be a crucial component of the NRTF process						

• What methodological approach is used to collect feedback?
  ○ Self-reported survey
  ○ Interview with healthcare staff
• How is feedback collected?
  ○ 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?
	International initiatives to integrate PROMs and patient-reported experience measures (PREMs) in data collection systems in achieving value-based healthcare differed in governance strategies and provided opportunities for usefulness at different health systems levels
	• Among the few initiatives that leveraged real-time data, a key strength identified was the ability to inform clinical and management changes more rapidly
	• The types of governance among data collection system initiatives identified from different countries were:
	1. national (England, U.K.)
	2. external third-party with regional government collaboration (Italy, Canada)
	3. national registries (Denmark, Sweden)
		Medium	No	3/9	2022	None	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
○ Patients and clinicians ○ Organizational leaders ○ Policymakers and system planners • For what purpose is real-time feedback collected? ○ To inform care decisions ○ 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 • Implementation of real-time feedback programs ○ Barriers to implementation • Facilitators to implementation	4. local team (Kenya) • EQ-5D-5L was an often-used PROM, though the selection of PROMs and PREMs in data collection systems depended on their intended use and care trajectory of interest • Strategies in selecting PROMs and PREMs included collaborative questionnaire development with patients and iterative validation, modification of questions for enhancement, and adaptation of questionnaires to local context • Data collection in the initiatives was done through mostly web-based methods in addition to phone surveys and paper ○ Phone surveys were limited to brief questionnaires and may be subject to interviewer or selection bias ○ Mail and paper collection may be costly and time-consuming • Data from the initiatives provided a means of benchmarking various health services relative to each other to inform care quality improvements and research • Barriers to implementing the data collection system included: ○ resistance from clinicians ○ challenges with administration and logistics ○ lack of training, time, tools, and resources (financial and human) • Facilitators to implementing the data collection system included: ○ having a champion for the initiative at different health systems levels, especially at the clinical level ○ involving patients in the development of the data collection system ○ communication through various media of information ○ clinician training and support						
• 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?	Efforts to integrate patient-reported experiences and outcomes into care practices (including electronic data collection and real-time feedback) have the potential to improve patient satisfaction and engagement, as well as communication among staff (24) • Barriers identified included inadequate resources and poor attitudes towards PROMs, privacy concerns, and confusion about goals and limited managerial support • Facilitators included clinician involvement in program planning, organizational culture being receptive to integrating feedback	Medium	No	5/9	2021	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
○ Home and community care ○ Primary care ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • When is real-time feedback collected? ○ During a clinical encounter ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians ○ Organizational leaders • 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	into practice, and real-time data use to facilitate immediate adjustments in patient care • Training and resources, and ensuring interventions, allow for customized PROM tools to meet specific patient needs were highlighted as important recommendations to ensure program uptake and success						

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
○ 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 • Implementation of real-time feedback programs ○ Barriers to implementation • Facilitators to implementation							
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic • For which sectors is real-time feedback collected? ○ Speciality care ▪ Surgical services • When is real-time feedback collected? ○ Hours or days following a clinical encounter • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes	Improvement of electronic collection of patient-reported outcomes (ePROs) and seamless integration with electronic health records (EHRs) is essential for improved clinical use and effectiveness of patient-reported outcome measures (PROMs) following surgery (25) • Only about one-third of included studies reported using ePROs to directly guide treatment plans ○ Real-time feedback was not prevalent and methods for patients to engage with healthcare professionals directly was limited • Integration with EHRs was absent in all 14 studies; the authors emphasized that integration with EHRs is essential for ePRO systems to be used in clinical practice, and this would allow for the improved delivery of care • It is suggested that further real-world clinical studies must be completed to examine the effects of meaningful and effective use of ePRO data collection systems following surgery	Medium	No	4/9	11 July 2019	Not available	None

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
○ Patient experience							
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Primary care • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions • 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	While real-world clinical data is lacking, real-time PRO data collection in oncology care may be effective if barriers including healthcare professional training and interpretation guidelines are implemented (26) • To improve the usage of PRO data, integration with electronic health records is essential; this will require additional costs and resources, but it is suggested that this is a pivotal aspect of successfully implementing PROMs into clinical practice • Guidelines for interpreting PROMs should be better developed to allow for effective clinical actions in response to PROs • It is suggested that literature pertaining to clinical usage of PROs in oncology care is lacking, and the authors emphasize the need for more real-world research pertaining to the implementation of PROs	Medium	No	4/9	2016	Not available	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
• Implementation of real-time feedback programs o Barriers to implementation o Facilitators to implementation							

Appendix 4: Key findings from single studies sorted by relevance

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Speciality care
• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To increase patient involvement in decision-making
  ○ To inform care decisions
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
  ○ Costs
	A weekly real-time electronic patient-reported outcome symptom questionnaire and real-time advice system combined with usual care for cancer patients was found to improve physical well-being (six and 12 weeks) and self-efficacy (18 weeks) without increasing hospital workload (10)
	• Patient Information and aDvice (eRAPID) was added to usual care for patients with colorectal, breast, or gynecological cancers initiating systemic treatment (chemotherapy with or without targeted therapies), consisting of online symptom questions conducted from home using the patient's own PC or mobile device at least weekly or else also when experiencing symptoms
	• Patients subsequently received immediate, severity-dependent advice on symptom management or a prompt to contact their local hospital
	• Symptom questions and advice were developed through a participatory design that involved patients and clinicians
	• Patients with eRAPID + usual care showed improved physical well-being at six and 12 weeks but no difference at 18 weeks compared to patients receiving usual care
	• Patients with eRAPID + usual care did not show any differences in hospital admissions or chemotherapy delivery (suggesting costs may also be similar in both groups) compared to patients with only usual care
	• Patient compliance with weekly symptom reporting was 64.7%, and was associated positively with physical well-being at 12 weeks
		High	*Publication date:* 2021
			
			Jurisdiction studied: U.K.
			
			Methods used: Phase III randomized controlled trial
				• None reported

• What real-time feedback is collected?
  ○ Patient-reported experience measures
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospital inpatient
• When is real-time feedback collected?
  ○ During a clinical encounter (while patients are still in hospital)
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
  ○ Interview with healthcare staff
	Implementing a near real-time feedback approach for measuring patient experiences in hospitals faces several barriers but can be successful when barriers are addressed promptly through ongoing support and relationship building (6)
	• Data collected from patients closer to the point of care, while still in hospital or shortly after
	• Implementing a near real-time patient feedback system in a cancer centre is feasible, with a high participation rate (79%) and good completion rate (67% for all scales), but faces challenges such as technology issues, time constraints, and initial limited staff engagement
	• Despite these challenges, the system revealed important patient-reported outcomes, including high rates of psychosocial distress
		High	*Publication date:* 9 November 2016
			
			Jurisdiction studied: Germany
			
			Methods used: Observational prospective study
				• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Others (e.g., a diary, meetings, workshops, support calls, a networking event) • How is feedback collected? ○ Healthcare clinic or hospital technology (e.g., computers, tablets) • By whom is real-time feedback used? ○ Patients and clinicians/staff • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level • Implementation of real-time feedback programs ○ Barriers to implementation • Facilitators to implementation	(62.1%) and need for psychological oncological support (53%), demonstrating its potential value in clinical care			
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians ○ Organizational leaders • 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	A Kaiser Permanente oncology centre implemented electronic patient-reported outcomes (ePROs) and found that they were beneficial for patient care and symptom management when effectively integrated into local workflows and supported through team collaboration (11) • ePROs were subsequently integrated into electronic medical records (EMRs) continuously to help track patient symptoms and inform care decisions and interventions • Successful deployment of ePROs requires robust infrastructure within a larger healthcare system • A dedicated care team is required for effective implementation • Key barriers include the need to multilingual surveys, making surveys accessible, and ensuring consistent patient participation • ePROs may help facilitate early symptom identification and management, enhance patient-practitioner communication, and decrease resource use through proactive care adjustments	High	*Publication date:* 2023 *Jurisdiction studied:* U.S. *Methods used:* Case study/feasibility study	• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
  ○ Patient experience
  ○ Costs
• Implementation of real-time feedback programs
  ○ Barriers to implementation
• Facilitators to implementation				

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Primary care
• When is real-time feedback collected?
  ○ During a clinical encounter
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Healthcare clinic or hospital technology (e.g., computers, tablets)
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
  ○ To inform learning and improvement at the organizational level
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
  ○ Patient experience
• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation
	The electronic patient-reported outcome system significantly increased the completion rates of health assessments, identified critical health issues (e.g., depression and anxiety), reduced paperwork for staff, and received positive feedback from both patients and providers for improving communication and care efficiency (4)
	• The study consisted of implementing an ePRO system that provided health questionnaires via tablets, integrated with the EHR to streamline data collection and improve patient-provider communication
	• This involved patients and clinical staff (including medical assistants and primary care providers) at three primary care clinic sites within Fenway Health
	• Addressing initial staff hesitations and ensuring seamless integration were found to be crucial for the program's success and sustainability
		High	*Publication date:* 2020
			
			Jurisdiction studied: U.S.
			
			Methods used: Mixed-method design
				• None identified

• What real-time feedback is collected?
  ○ Patient-reported experience measures
  ○ Patient-reported outcome measures
  ▪ Condition-specific
	Using the myHealthE system for electronic patient-reported outcome measures (PROMs) led to a significant increase in Strengths and Difficulties Questionnaire (SDQ-P) completion rates among caregivers, with a completion rate of 69% compared to just 12% for paper-based methods (22)	High	*Publication date:* 2022
			
			Jurisdiction studied: U.K.
				• None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• For which sectors is real-time feedback collected?
  ○ Speciality care
• When is real-time feedback collected?
  ○ Immediately following a clinical encounter
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Patient portals
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
  ○ To inform learning and improvement at the professional level
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
  ○ Provider experience
	• The study focused on evaluating the feasibility and effectiveness of a web-based platform for collecting electronic PROMs in Child and Adolescent Mental Health Services
	• PROMs are standardized tools for collecting patients' perceived health status and are used to measure symptoms, assess intervention success, and facilitate communication between patients and practitioners
	• Electronic patient-reported outcome measures (ePROMs) are less time-consuming, require less administrative effort, cost less, and produce more accurate responses compared to paper-based methods
			Methods used:
			Feasibility pilot study with a randomized controlled trial (RCT) component	

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Surgical services
• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
	Collecting daily micro-surveys of patient-reported health-related quality of life using smartphones among patients recovering from cancer surgery is feasible, with micro-surveys contributing to more SF-36 collection compared to intermittent full-length SF-36 (17)
	• Daily micro-surveys of patient-reported outcomes of health-related quality of life were administered to patients recovering from cancer surgery using a smartphone application
	• Micro surveys consisted of five randomly selected items from the Adult measures of general health and health-related quality of life: Medical Outcomes Study Short Form 36-Item (SF-36) until the entire SF-36 was administered weekly
	• Compared to paper-based methods, during inpatient visits, or separately scheduled interviews, smartphone-based daily micro-surveys has the potential to reduce human, time, and financial resource costs
	• An additional advantage may be that patients are able to fill out surveys in their natural environment, thereby potentially providing a more accurate representation of their health-related quality of life
		High	*Publication date:* 2021
			
			Jurisdiction studied:
			U.S.
			
			Methods used:
			Prospective study using micro-surveys (daily) and full-length (administered at four, 12, and 24 weeks)
				• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes				

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Speciality care
• When is real-time feedback collected?
  ○ During a clinical encounter
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Patient portals
  ○ 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
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
  ○ Provider experience
• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation
	The routine electronic monitoring of health-related quality of life using patient-reported outcome measures was feasible and had high compliance among breast, colorectal, and lung cancer patients but rarely translated into physicians' change in provided care (14)
	• Patient-reported outcomes (PROs) are assessed by patients directly based on their perception of their disease and treatment
	• The study intended to improve patient-centred care through the routine electronic monitoring of the health-related quality of life (HRQoL) PROMs in breast, colorectal, and lung cancer patients
	• Patients were administered the European Organization for Research and Treatment against Cancer QLQ-C30 questionnaire along with cancer-site-specific items (QLQ-BR23 for breast, QLQ-CR29 for colorectal or QLQ-LC13 for lung), as well as the EQ-5D 3L, using the computer-based Health Evaluation System software
	• Questionnaires were completed prior to each patient's clinical visit over a period of four months, either at home through a secure portal or in the waiting room with a provided tablet and the help of a clinical research assistant if needed
	• Completion of the questionnaires was immediately followed by a graphical display of the HRQoL results which were added to the patient electronic medical record
	• Individual and group training were provided to physicians for using the questionnaire software and interpreting HRQoL results
	• Most patients (94.9%) were compliant with the completion of the questionnaires (each meeting a certain threshold of the total number of administered assessments)
	• Most physicians reviewed HRQoL results (73.1%) but did not take action on them (prescribed supportive care in 8.3% of visits; adapted their patient management in 5.2% of visits)
	• The combination of a multidimensional questionnaire (like the QLQ-C30) with population-specific items that was administered may facilitate a comprehensive measurement of patient experience
	• Barriers to implementing the routine electronic monitoring of HRQoL PROMs in daily procedure included organizational constraints (e.g., human and financial resources, and institutional strategy), physician-related constraints (e.g., time, training in the use and interpretation of the specific PROM, technology, preference for conversational
		High	*Publication date:*
			2021
			
			Jurisdiction studied:
			Besançon, France
			
			Methods used:
			Single-centre, prospective feasibility study
				• None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	evaluations), and patient-related constraints (e.g., intervention burden, technology, lack of follow-up on issues surfaced in PROMs) • As physicians become more familiar with their patients, they may not perceive HRQoL scores to be useful or be comfortable discussing them with patients • The routine use of HRQoL assessments may uncover a range of unrelated health problems that physicians may not be equipped to deal with			

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Surgical services
• When is real-time feedback collected?
  ○ During a clinical encounter
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ 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
• 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
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
  ○ Patient experience
  ○ Provider experience
	Collection of real-time feedback of patients' health information to oncologists has the potential to improve their symptom control, but may have little impact on emotional well-being (12)
	• Participants responded to a computerized survey in the outpatient waiting room while waiting for their appointment with oncologist (follow-up surveys completed at each of their next three visits that followed)
	• Computer survey collected information on demographic and cancer characteristics (e.g., age, cancer site, remission status), physical symptoms (e.g., nausea, vomiting, weight loss), levels of anxiety and depression (assessed by the Hospital Anxiety and Depression Scale (HADS), and perceived care needs of patient (assessed by the truncated version of the Supportive Care Needs Survey (SCNS))
		High	*Publication date:* 2006
			
			Jurisdiction studied: New South Wales, Australia
			
			Methods used: Pilot Study
				• None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Surgical services
• When is real-time feedback collected?
  ○ During a clinical encounter
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ 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
• 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
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
  ○ Patient experience
	The Patient Reported Outcome Measures for Personalized Treatment and Care (PROMPT-CARE) is a highly acceptable eHealth system to capture real-time feedback from cancer patients and support clinical decisions in oncology settings (13)
	• The PROM tools incorporated into the eHealth system include the Distress Thermometer with the problem checklist, the Edmonton Symptom Assessment Scale (ESAS), and the Supportive Care Needs Survey-Screening Tool 9 (SCNS-ST9)
	• Patients completed PROMPT-CARE surveys on initial visit and then every two to four weeks (if on active treatment) or monthly (if on follow-up)
	• Participants completed assessments in the waiting area on a healthcare clinic tablet device (if on active treatment), while follow-up patients either completed the assessments from home (link sent to their email) or at the clinic
		High	*Publication date:* 2017
			
			Jurisdiction studied: New South Wales, Australia
			
			Methods used: Mixed methods
				• None identified

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
• For which sectors is real-time feedback collected?
  ○ Speciality care
• For which sectors is real-time feedback collected?
  ○ Long-term care
• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
	Gaps in remote symptoms monitoring with ePROMS must be addressed in order to effectively implement these reporting systems into real-world clinical practices and continuous maintenance of these programs is essential for their effective use (15)
	• Adaptations to remote symptom monitoring systems should be considered at least every three months to ensure maintenance of the program and to address any changes required
	• For patients with cancer, continuous monitoring and reporting of their symptoms is essential
	• Therefore, reducing barriers to ePROMs is essential, and adaptions to reporting systems must be made when necessitated
		High	*Publication date:* 28 October 2022
			
			Jurisdiction studied: U.S.
			
			Methods used: Mixed methods
				• None

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	• Survey completion should be monitored in real-time, and support should be provided to patients who are unable to or have not been completing their surveys • The symptoms questioned in the electronic survey should be symptoms with an actionable treatment • A physician must be available to monitor responses in a timely manner; this may encourage patients to continue to use platforms that electronically monitor their symptoms • Surveys should be customizable to the patients' needs in order to reduce survey fatigue • Responsibility should be assigned to healthcare workers to ensure that these systems are monitored effectively			
• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • When is real-time feedback collected? ○ 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 • How is feedback collected? ○ Healthcare clinic or hospital technology (e.g., computers, tablets) • By whom is real-time feedback used? ○ Patients and clinicians ○ Organizational leaders • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions	Implementing a successful electronic patient-reported outcome measures program for joint replacement surgery requires customization of the program platform to adapt to program needs, cost minimization, and online electronic data collection with the support of human and financial resources; barriers could include overburdening staff and patients to use the platform and hospital staff turnover that can affect handover of associated tasks to new staff (23) • This study explored the development and implementation of an electronic data collection and reporting system by a national registry for PROMs as well as a cost breakdown of developing and maintaining a sustainable, nationwide electronic PROMs program • The electronic data of preoperative and post-operative (six-month) hip, shoulder, and knee replacement surgery was collected from 44 Australian hospitals that use the Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR) • Information collected from patients by the pilot's in-house software, RAPID, included electronic consent, preoperative/postoperative PROMs, and real-time dashboard reporting to allow patients to compare their PROMs responses to the national averages ○ Once registered using a tablet provided through the pilot, patients could provide consent and complete PROMs immediately or at a later time ○ Automated email and text message reminders were sent to patients from RAPID to complete PROMs both perioperatively and six months post-operatively	High	*Publication date:* April 2022 *Jurisdiction studied:* Australia *Methods used:* Pilot study	• None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ To inform learning and improvement at the professional level ○ To inform learning and improvement at the organizational level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Patient experience ○ Costs • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	• Orthopaedic surgeons and designated hospital staff were able to access patient responses in RAPID when consent was given, and RAPID allowed for the integration of PROMs data collected by third parties • Hospital registration reportedly improved during the pilot, from a registration rate of 44.85% of procedures in the first three months of data collection to more than 60.2% after 12 months of data collection • The majority of the costs associated with the pilot program were attributed to staffing costs and software development of RAPID as well as security of patient data • Enablers for establishing a PROMs program identified in the study included successful cost minimization, online electronic data collection, and customization of the RAPID platform, while barriers included overburdening staff and patients to use the platform and hospital staff turnover that impacted handover of associated tasks to new staff • Given the success of the pilot program, the planning of a national rollout of the program in Australia commenced with government funding			
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient • When is real-time feedback collected? ○ During a clinical encounter ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Healthcare clinic or hospital technology • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions	Capturing PROMs in older adults with end-stage renal disease on hemodialysis using an iPad-based electronic application tool proved to be an efficient, easy-to-use method to monitor patient symptom burden and quality of life (20) • This study assessed the feasibility of implementing K-Pal, an iPad application-delivery assessment tool for collecting PROMs data of older adult patients with end-stage renal disease (ESRD) on hemodialysis (HD) between June and August 2017 • Of the 22 patients initially enrolled, 82% were retained after six months, 63.6% were female and 81.8% were African American • Assessments were carried out while patients were undergoing HD; a research assistant would hand the patients the iPad loaded with the K-Pal app • Responses were immediately scored and sent to the primary nephrologist, and if a patient's responses indicated suicidal ideation, an alert would be sent to the nurse who would then contact the nephrologist to intervene immediately • Most patients found the K-Pal app easy to use but some found that it was somewhat overwhelming with the amount of questionnaires and considering patient fatigue from HD treatment ○ Some solutions to mitigate these challenges included spacing out symptom assessment, numbering the survey questionnaires, and creating an introductory video for first-time users	High	*Publication date:* September 2020 *Jurisdiction studied:* U.S. *Methods used:* Feasibility study	• Race/ethnicity/ culture/ language

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
  ○ Patient experience
• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation
	• Study results indicated that electronic PROMs within a dialysis unit may be an efficient way to monitor overall symptom burden and quality of life			

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospital inpatient
  ▪ Surgical services
• When is real-time feedback collected?
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• By whom is real-time feedback used?
  ○ Patients and clinicians
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation
	Early success was reported in the implementation of electronic patient-reported outcomes using an online portal for patients with cancer; systematic implementation steps were taken to ensure that patients completed the survey at home or while in the waiting room prior to the clinical visit and its integration into the existing electronic health record system at the hospital (18)
	• The implementation of electronic patient-reported outcomes involved the development of a committee including those with oncology specialties, physicians, administrators, IT teams, and researchers
	• The patient-reported outcomes survey was offered before the visit on a patient portal, where they were provided a one-week window to complete the survey so that they can review the results with their provider during the appointment
	• The hospital provided the patient a tablet in the waiting room if the survey was not completed, which was then automatically uploaded to the electronic health record
	• Baseline scores were taken during new patient visits and then collected once a week during active treatment for pain interference, fatigue, and physical function
	• Depression was collected once a month, or once every three months, quarterly, every six months, or yearly dependent on their survivorship year
	• Roll-out involved gradual implementation with the use of a physician champion, training of clinical staff of each unit, all while being mindful of the culture and context of each clinical unit
	• The authors noted early success in the implementation of patient-reported outcomes among patients with cancer
		High	*Publication date:* 20 January 2023
			
			Jurisdiction studied: Detroit, U.S.
			
			Methods used: Quantitative (retrospective survey)
				• None reported

• What real-time feedback is collected?
  ○ Patient-reported experience measures
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospitals
• When is real-time feedback collected?
	Based on preliminary results and feedback from practitioners, the patient-reported experience measures (PREMs) initiative outlined in this paper has the potential to enhance the integration of PREMs into the daily practices of healthcare professionals and it also supports patient-driven quality improvement mechanisms and fosters cultural and behavioural change through various innovations it introduces (5)	High	*Publication date:* 2020
			
			Jurisdiction studied: Italy
				• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Immediately following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey ○ Interview with healthcare staff • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform health services planning at the organizational level ○ To inform health services planning at the system level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Patient experience	• This paper presents an empirical case of PREMs innovation in Italy to foster patient data use up to the ward level by keeping strengths and addressing weaknesses of previous PREMs survey experiences • The ongoing initiative, currently adopted by 21 hospitals of two Italian regions systematically collects patient experience data to provide: ○ standard experience data for trend monitoring and benchmarking within and among healthcare organizations and regions ○ real-time narrative feedback, highlighting episodes, people, and behaviours that significantly impacted the patients' experience, which healthcare organizations can use to recognize outstanding individuals and learn from successful practices • In the narrative feedback, patients take into consideration their whole experience by reporting on what and who really matters to them • Narrative feedback can bring to light fundamental aspects of the patient experience, such as compassion and humanity, which are not specifically addressed by closed-ended questions • According to the practitioners' feedback, the volume of positive feedback provided by patients can be a lever to encourage, motivate, and value clinicians, nurses, and care workers • PREMs allows for the monitoring of the care assistants' contribution to the positive experience of patients, which is usually difficult to measure		*Methods used:* Action research and case series study	
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care • When is real-time feedback collected? ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?	Incorporating ePROMs into post-radiation therapy care is a feasible option that can enhance care after breast irradiation by providing patients with rapid access to care and optimizing the distribution of follow-up appointments based on their individually assessed needs (19) • This study aims to explore patients' perceptions regarding the value of the ePROM system, ease of its use, and barriers to using the system after breast irradiation • From July–November 2021, evaluation surveys were posted to 100 people who had received radiation therapy to their breast to explore their experience of using the ePROM • Although only a few participants reported significant side effects, most recommended the ePROM, noting it as a valuable source of support • Those who did experience significant side effects found the system to be both timely and effective • Barriers to accessing the ePROM included technical problems with the link, concerns about confidentiality, and forgetting to use it • An association was found between education level and ability to access the ePROM with those with higher levels of education accessing the ePROM most frequently	High	*Publication date:* 2023 *Jurisdiction studied:* Northern Ireland *Methods used:* Pilot service evaluation	• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Patient experience	• Breast irradiation schedules vary considerably so the timing of ePROMs post-radiation therapy should be optimized to capture and manage side effects for each patient as side effects arise in real time • Post-radiation therapy, ePROMs offer reassurance and support to patients while waiting for their first post-RT follow-up appointment			
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic • For which sectors is real-time feedback collected? ○ Speciality care ▪ Surgical services • When is real-time feedback collected? ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians ○ Policymakers and system planners • For what purpose is real-time feedback collected? ○ To inform care decisions	Rapid patient-reported outcome measures using automated text messaging can be used to support healthcare and policymaker decision-making (21) • Data was collected using automated text messaging to collect patient reported pain intensity, ability to manage pain, and opioid use in patients who had received a urological procedure during a 28-day postoperative period • Approximately half of participants (51.8%) completed the text-message survey • Participants were mostly men, white, had private insurance, and did not use opioid prior • This study concluded that using real-time patient-reported data via text messaging can support healthcare workers and policy leaders in forming guidelines for best practice ○ The authors noted that since they had fewer racially diverse responses, their proposed guidelines could yield racially biased results, emphasizing the need for participant representation	High	*Publication date:* December 2022 *Jurisdiction studied:* U.S. *Methods used:* Cross-sectional	• Race/ethnicity/culture/language
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient • When is real-time feedback collected? ○ During a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Healthcare clinic or hospital technology (e.g., computers, tablets) • By whom is real-time feedback used?	Implementing an electronic real-time assessment of PROs in routine cancer care is feasible and well-accepted by patients, but faces challenges in terms of staff engagement and integration into clinical workflows (16) • This study implemented an electronic real-time assessment of PROs in a comprehensive cancer centre, using an adaptive, self-administered electronic questionnaire on tablet PCs completed by patients before their first consultation • It aimed to describe the development, implementation, completeness, and initial results of an electronic real-time assessment program for collecting PROs at a tertiary referral cancer centre • The system provided immediate access to patient data in the hospital information system for use in clinical decision-making • The program achieved a 79% participation rate among approached patients, with 67% of participating patients providing complete information on all PRO-related scales	High	*Publication date:* 2016 *Jurisdiction studied:* Germany *Methods used:* Observational prospective study	• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform care decisions and potentially improve patient care • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	• Key barriers included technical issues with tablets and connectivity, time constraints for questionnaire completion before consultations, limited physician usage of PRO data during consultations initially, and lower participation rates among older patients • Major facilitators included ongoing technical support, flexibility in the implementation approach, continuous feedback collection from staff and volunteers, and increasing acceptance among medical staff over time			
• 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 ○ Public health • What methodological approach is used to collect feedback? ○ Self-reported survey ○ Interview with healthcare staff • How is feedback collected? ○ 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 • For what purpose is real-time feedback collected? ○ To inform care decisions ○ 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	International initiatives to integrate PROMs and PREMs in data collection systems in achieving value-based healthcare differed in governance strategies and provided opportunities for usefulness at different health systems levels (27) Features • Among international initiatives of data collection systems using PROMs and PREMs, governance structures often consisted of a steering committee with government, clinician, and patient representation • In adhering to data privacy and security regulations, data collection systems used unique log-in credentials or national identifiers coupled with password and double authentication methods • Different users of the system have different levels of access – clinicians could access only their patients' data while managers could access only aggregated data • PROMs and PREMs data could be simultaneously collected at home, in the waiting room, or in a hospital stay • PROMs and PREMs informed clinical monitoring and patient self-management at the micro level, care quality improvement by organizational managers at the meso level, and epidemiological understanding at the macro level Implementation • Patient involvement in the implementation varied; they could be involved in PROMs and PREMs questionnaire development to assist with relevance and comprehensibility, testing said questionnaires, and evaluating the data collection system to report on issues and feedback • The implementation of data collection systems generally began with care trajectories for elective surgery before widening the scope to include those of chronic diseases • Generic and specific PROMs and PREMs were selected for the development of data collection systems which could be modified for	Medium	*Publication date:* 2024 *Jurisdiction studied:* Australia (New South Wales), Denmark, Italy (Tuscany), Norway, U.K. (England, Wales) *Methods used:* Mixed (key informant interviews, scoping review)	• None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation
	better contextualization (e.g., adding questions, combing parts of PROMs and PREMs questionnaires)
	
	Barriers
	• Implementing a data collection system in primary care settings was found to be challenging due the stakeholders and infrastructure required
	• The variety of different platforms for data collection, questionnaire administration, and results visualization that may exist necessitates streamlining
	• Skepticism among professionals about the usefulness of PROMs and PREMs at higher levels in the health system may limit their engagement
	
	Facilitators
	• The different nature between clinical use and systemic use of PROMs and PREMs informed their selection in a data collection system, and it was critical that questionnaires were context-appropriate through validation and adaptation
	• Considerations to improve patient and professional engagement in adopting PROMs and PREMs include:
	  ○ being with the patient during data collection
	  ○ providing different language options for questionnaires
	  ○ implementing reminder systems for questionnaire completion
	  ○ communicating data collection objectives and benefits regularly
	  ○ automating data collection			

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Home and community care
• When is real-time feedback collected?
  ○ During a clinical encounter
  ○ Multiple times
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Healthcare clinic or hospital technology (e.g., computers, tablets)
• By whom is real-time feedback used?
	Electronic patient-reported outcome measures can improve monitoring, assessing, and symptom managing in home palliative cancer care patients (28)
	• This study looked at the feasibility of implementing the electronic integrated palliative care outcome scale in home palliative cancer care
	• This study compared outcomes in patients who received standard palliative care and those who received standard care and the ePROMs
	• Healthcare staff provide the self-report measure on iPads for patients to complete during each visit
	• The report is used to create a comprehensive health summary that can be used to monitor patients progress over time
	• The outcome measure was reported to be feasible with a high recruitment rate (74%) and level of completeness
	• A decrease in unplanned visits was seen, suggesting more effective monitoring during scheduled visits
		Medium	*Publication date:* 19 March 2024
			
			Jurisdiction studied: Milan
			
			Methods used: Quasi-experimental pilot study
				• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Patient experience ○ Provider experiences	• A positive impact on monitoring, assessing, and managing symptoms were seen for providers			
• What real-time feedback is collected? ○ Patient-reported outcome measures • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Healthcare clinic or hospital technology (e.g., computers, tablets) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience ○ Provider experience • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	The integration of a patient-reported outcomes survey into the electronic medical record system at the University of Texas Anderson Cancer centre, while successful, took multiple steps to address the reported barriers such as attitudes and behaviours of patients and providers, lack of existing infrastructure, technology challenges, and knowledge and skills related to interpreting and accessing the survey (29) • The study describes the development and implementation of a patient-reported outcomes survey that was built into the University of Texas Anderson Cancer centre's electronic medical record system in survivorship clinics • The study defined patient-reported outcomes as the influence of their disease and the treatment on their health status or quality of life • The implementation process included the establishment of an executive leadership committee including expert clinical providers, administrative leaders, social workers, nutritionists, electronic health records experts, and patient partners • They met monthly to discuss challenges, assist with the technical aspects such as integrating patient-reported outcomes into the existing electronic medical record system, designing educational materials for staff and patients, and developing an evaluation plan to monitor progress • The committee identified barriers to the adoption of patient-reported outcomes such as attitudes and behaviours from patients, providers, and other stakeholders, lack of an infrastructure to support providers, knowledge and skills related to interpreting and accessing the survey through the electronic medical record, disruptions to clinical workflow (e.g., when and how to distribute surveys without interrupting clinical operations), and technology (e.g., problems with interoperability) • The study described the additional multiple implementation processes such as the selection of measures through peer-review literature and consultations, approval from the patient survey governance committee, development of educational materials, pilot test in a clinic, feasibility test, and assessment of patient acceptance of the survey	Medium	*Publication date:* 3 September 2021 *Jurisdiction studied:* Texas, U.S. *Methods used:* Case study	• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• What real-time feedback is collected?
  ○ Patient-reported experience measures
• For which sectors is real-time feedback collected?
  ○ Primary 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
• By whom is real-time feedback used?
  ○ Patients and clinicians
  ○ Organizational leaders
• 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
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
  ○ Provider experience
	Primary care patient experience varied across four case studies examining the integration of real-time collection of patient experience data, between 99% and 87% very good or excellent experience ratings, with clinics reporting boosted morale because of the program implementation (30)
	• Three cases of interprofessional primary care clinics and one case of a public health organization in Ontario integrated real-time collection of patient experience data, highlighting the variation in how PREMs are deployed and used in primary care
	• Resources needed to support the ongoing use of the programs were highlighted as a key success factor
		Medium	*Publication date:* 2023
			
			Jurisdiction studied: Ontario, Canada
			
			Methods used: Multiple, mixed methods case studies
				• None reported

• What real-time feedback is collected?
  ○ Patient-reported experience measures
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospital inpatient
• When is real-time feedback collected?
  ○ During a clinical encounter
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Healthcare clinic or hospital technology (e.g., computers, tablets)
	An in-hospital patient-experience questionnaire on in-room TVs was successfully implemented to integrate real-time feedback in a children's hospital, but showed no impact on experience survey results (31)
	• Negative responses prompted additional questions for clarification, and real-time alerts were sent to unit leaders for potential service recovery
	• In terms of user experience, the program reduced interruptions by adjusting launch timings and frequency
	• The implementation of the program appeared to be a cost-effective way of soliciting real-time feedback, although initial cost can present a potential barrier to implementation, especially tablet or kiosk purchases
		Medium	*Publication date:* 2024
			
			Jurisdiction studied: U.S.
			
			Methods used: Case study
				• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• By whom is real-time feedback used?
  ○ Patients and clinicians
  ○ Organizational leaders
• For what purpose is real-time feedback collected?
  ○ To increase patient involvement in decision-making
  ○ To inform care decisions
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
  ○ Provider experience
  ○ Costs
• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation				

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospital inpatient
  ▪ Surgical services
• 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
• How is feedback collected?
  ○ Patient portals
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
  ○ Researchers
• For what purpose is real-time feedback collected?
	A mobile application for collecting real-time PROs integrated into an existing surgery recovery program showed high patient adoption, engagement, and satisfaction (32)
	• A pilot study was conducted to implement a mobile application collecting real-time PROs as part of an established surgery recovery program, Enhanced Recovery After Surgery (ERAS®), in the context of hepatopancreatobiliary surgery
	• The mobile application has a patient- and surgeon-specific portal for each patient's surgical plan where the language of materials was provided at a sixth-grade English level to patients
	• Before surgery, patients were prompted to complete anxiety and quality-of-life benchmark surveys through scheduled reminders from the mobile application
	  ○ Quality-of-life surveys included the abbreviated Quality of Recovery (QoR-15) and PROs Measurement Information Systems (RPOMIS)
	• On the day of surgery and throughout the hospital stay, patients were prompted to complete daily surveys for monitoring symptoms, pain, nausea, opiate use, anxiety, and quality-of-life
	• After discharge, patients were prompted to complete the same daily surveys for 30 days followed by a survey for their experience with the application
	• The mobile application was designed to be used by members of a patient's support system (family and friends) whose involvement was encouraged
		Medium	*Publication date:* 2019
			
			Jurisdiction studied: Charlotte, North Carolina, U.S.
			
			Methods used: Prospective, single-group, pilot study
				• Not identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ To inform health services planning at the organizational level ○ To support research efforts • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Patient experience ○ Provider experience • Implementation of real-time feedback programs ○ Facilitators to implementation	• Patient adoption and engagement with the mobile application was 93%, 88%, and 52% before surgery, immediately after surgery, and after discharge, respectively • The overall PRO response rate for all surveys was 57% and patient satisfaction rate with the mobile application was 86% • Through the pilot, a pathway for immediately uploading patient-reported pain and nausea scores to the electronic medical record was also achieved • The pilot demonstrated a way to leverage mobile health technology to enable patient data tracking that does not create additional burdens for health providers • The use of mobile application for collecting PROs helped to address the pitfall of traditional PROs being obsolete from collection to analysis and reporting • This study focused on mobile application engagement and survey responsiveness; they appear to inform health services planning at the organizational level, while also supporting research efforts, given the novel method to collect real-time PROs to complement an existing surgery recovery program at a tertiary care centre			
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To inform care decisions • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	The development of an Australian eHealth system integrated into oncology hospital systems using patient-reported outcomes to inform personalized treatment and care highlighted the need for expert collaboration to create clinical pathways while considering response burden, IT security, and resource feasibility of the location in which it is being implemented (33) • Patient-reported Outcomes for Personalized Treatment and Care (PROMPT-Care) is an Australian eHealth System that is fully integrated into hospital oncology information systems to allow for real-time routine collection of patient-reported outcomes from oncology outpatients • It was established using expert advisory groups that collaborated to determine domains of patient care, select patient-reported outcomes and identify cut-offs for clinical action, and develop clinical pathways and actionable recommendations when patient-reported outcomes went above designated thresholds • When selecting PROs, developers should consider patient response burden and prioritize PROs linked to clinical intervention • Consultation with hospital information technology services should be sought early and often throughout the program development process to ensure secure PRO data transfer	Medium	*Publication date:* 2019 *Jurisdiction studied:* Australia *Methods used:* Case study/how-to guide	• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	• When considering thresholds for action for each PRO, cancer centres should consider an acceptable balance between false positives and false negatives, which can potentially impact centre workload • Recommendations issued by the system should take into account availability of local services and resources, and should be reviewed to ensure feasibility in the clinical setting			

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Generic
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Speciality care
• When is real-time feedback collected?
  ○ During a clinical encounter
• What methodological approach is used to collect feedback?
  ○ Self-reported survey
• How is feedback collected?
  ○ Healthcare clinic or hospital technology (e.g., computers, tablets)
• By whom is real-time feedback used?
  ○ Researchers
• For what purpose is real-time feedback collected?
  ○ To support research efforts
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Patient experience
• Implementation of real-time feedback programs
  ○ Barriers to implementation
  ○ Facilitators to implementation
	The use of patient-reported outcome questionnaires for routine assessment was found to be moderately acceptable among cancer outpatients (34)
	• The study investigated cancer patients' willingness to regularly complete PRO questionnaires and its associations with clinical, demographic and survey characteristics
	• One of six validated PRO questionnaires followed by a locally developed acceptability questionnaire (10 items on a five-point Likert scale) were administrated on a tablet to each patient; the total number of questions to be answered ranged from 43 to 86
	1. Chemotherapy toxicity
	  ▪ PRO-CTCAE version 1.0; 68 questions
	2. Sleep and fatigue 1
	  ▪ Insomnia severity index and Fatigue Scale; 43 questions
	  ▪ Health utility score questions and EQ-5D-3L; 7 questions
	3. Sleep and fatigue 2
	  ▪ Insomnia severity index and Fatigue Scale; 36 questions
	4. Pain
	  ▪ Brief Pain Inventory and EQ-5D-3L; 47 questions
	5. Physical function
	  ▪ World Health Organization Disability Assessment Schedule, Health Assessment Questionnaire, Disability Index, PRO-Eastern Cooperative Oncology Group and EQ-5D-3L; 73 questions
	6. Combination of pain and physical function
	  ▪ Brief Pain Inventory, World Health Organization Disability Assessment Schedule, Disability Index and EQ-5D-3L; 86 questions
	• Most surveys were administered in the waiting rooms at the outpatient clinic
	• Most patients expressed willingness to complete the PRO surveys during every visit (58%), found it useful to tell clinicians how they felt physically and emotionally (77%), did not feel that their visit was made more difficult by survey completion (93%), and were satisfied with
		Medium	*Publication date:* 2019
			
			Jurisdiction studied: Toronto, Ontario, Canada
			
			Methods used: Prospective, cross-sectional study
				• Race/ ethnicity/ culture/ language (exploratory analysis)

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	answering on an electronic tablet (89%) but did not want to see a results printout (72%) • Half of the patients reported the PRO survey questions being personally irrelevant (50%) and wanted the information kept in their notes (51%) • PRO questionnaire content and relevance may facilitate its acceptability as the time required for survey completion was not found to correlate with acceptability • PRO questionnaire acceptability was higher among middle–age (40-65 years), white, Canadian-born, primary English speakers which appear to suggest ethnocultural factors as potential barriers to acceptability • Investigators presented the PRO questionnaires as mostly a research study to patients as opposed to providing information on patient experience to clinicians			

• 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?
  ○ Speciality care
  ▪ Hospital inpatient
• When is real-time feedback collected?
  ○ 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
• How is feedback collected?
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Organizational leaders
  ○ Researchers
• For what purpose is real-time feedback collected?
  ○ To inform learning and improvement at the professional level
  ○ To inform learning and improvement at the organizational level
  ○ To support research efforts
	A web-based, systematic, and continuous collection of patient-reported outcome measures and patient-reported experience measures was feasible among patients hospitalized for chronic heart failure (35)
	• PREMs were created for gathering information on patient experience with healthcare services as a way to improve care quality
	• PROMs longitudinally collect information to assess effectiveness in a clinical trial context, or information on individual functional, psychological, and social outcomes for improving patient health
	• The pilot study investigated the feasibility of a web-based, systematic, and continuous collection of PROMs and PREMs data for those hospitalized for chronic heart failure; patients were assessed at discharge and at one, seven, and 12 months after discharge through a personal online questionnaire link
	• For PROMs, the Kansas City Cardiomyopathy Questionnaire-12 (KCCQ-12), the Self-care heart Failure Index (SCHFI; 16 or 22 items depending on the patient), and a question on perceived health in the preceding week were administered
	  ○ The KCCQ-12 was not administered at discharge, but was used at each subsequent follow-up
	• For PREMs, the research team designed and administered specific questions that were appropriate for each follow-up timepoint
	  ○ At discharge, questions were on quality of care before and during hospitalization (9 items)
	  ○ At one month after discharge, questions were on experience of care during hospitalization, discharge management, and organization of home care (24 items)
		Medium	*Publication date:*
			2020
			
			Jurisdiction studied:
			Pisa, Italy
			
			Methods used:
			Single-site pilot study
				• Not identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Provider experience
• Implementation of real-time feedback programs
  ○ Facilitators to implementation
	○ At seven and 12 months after discharge, questions were on topics ranging from clinician monitoring, follow-up care coordination, home care, out-of-pocket expenditure, acute events, pharmaceutical dimensions, and follow-up visits (11 items)
	• PROMs improved incrementally on average among patients over the course of the follow-up period
	• The use of PROMs and PREMs data was intended for improving organizational processes, monitoring the work of hospital staff, and for interprofessional coordination
	• PROMs and PREMs may need to be collected in an integrated manner as patient experience could be influenced by their perception of outcomes and vice versa			

• What real-time feedback is collected?
  ○ Patient-reported outcome measures
  ▪ Condition-specific
• For which sectors is real-time feedback collected?
  ○ Speciality care
  ▪ Hospital inpatient
  ▪ Surgical services
• When is real-time feedback collected?
  ○ 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
• How is feedback collected?
  ○ Patient's own technology (e.g., computers, tablets, smartphones)
• By whom is real-time feedback used?
  ○ Patients and clinicians
• For what purpose is real-time feedback collected?
  ○ To inform care decisions
  ○ To inform learning and improvement at the professional level
• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
  ○ Health outcomes
	Real-time patient-reported information can be used to determine how well cancer care physicians understand the severity of conditions their patients experience (36)
	• In this study, electronic patient-reported outcomes (e-PRO-CTCAE) were compared to physician-assessed outcomes (NCI-CTCAE) of 50 cancer patients at an outpatient gynecological cancer centre from July 2021 to December 2022
	• e-PRO-CTCAE and NCI-CTCAE were both evaluated at each instance of chemotherapy and two weeks after; in addition, PRO-CTCAE was collected weekly using electronic PRO (e-PRO), which allows for real-time patient input and monitoring
	  ○ Patients downloaded the e-PRO app on their mobile devices and completed the PRO-CTCAE questionnaire
	• The study results indicated that physicians tend to underestimate most adverse events of patients (e.g., joint pain, nausea constipation, insomnia), but they had a good understanding of peripheral neuropathy
		Medium	*Publication date:* October 2023
			
			Jurisdiction studied: Japan
			
			Methods used: Case control study
				• None identified

• What real-time feedback is collected? ○ Patient-reported outcome measures	Routine patient-reported outcomes for heart failure that could be embedded into routine clinical care, optimized with the hospital workflow,	Medium	*Publication date:* 15 January 2020	• Not reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient • What methodological approach is used to collect feedback? ○ Self-reported survey • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Provider experience • Implementation of real-time feedback programs ○ Barriers to implementation • Facilitators to implementation	or other considerations for collecting outcomes when a patient cannot provide the information were identified as facilitators, whereas burden and language could pose as barriers for providers (37) • The authors interviewed physicians, advance practice providers, nurses, study coordinators, physician trainees, and office administrative personnel from five heart failure programs to discuss the implementation experiences of a patient-reported outcome information system • The major barriers included the burden (including survey fatigue) and language or health literacy related to completing patient-reported outcomes • The facilitators included embedding patient-reported outcomes into routine clinical care, finding ways to optimize workflow (e.g., appropriate time and place to have patients complete these assessments such as before an appointment in an electronic collection system, integration into electronic health record), or have a patient proxy or a nurse if the patient cannot fill the assessment • The providers also indicated that the data collected and presented should be user friendly		*Jurisdiction studied:* U.S. *Methods used:* Qualitative (focus groups)	
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes	Smartphone-based daily questionnaires for individuals with bipolar disorder appear to be an option for long-term daily monitoring of their symptoms (38) • The participants included those with diagnosed bipolar disorder who were predominately female • The authors compared a weekly standardized questionnaires on an online website that included four scales (i.e., Altman Self-rating Mania scale, Quick Inventory of Depressive Symptomology Self-Report, Generalized Anxiety Disorder, and EQ-5D) with a daily questionnaire on a smartphone, which the participants completed in the evening during a pre-specified time based on their convenience • The authors concluded that the smartphone-based daily questionnaire is a potential option for long-term daily monitoring among participants with bipolar disorder, particularly for monitoring mood and anxiety day to day	Medium	*Publication date:* 15 November 2016 *Jurisdiction studied:* England *Methods used:* Case-control observational (with gender and age matching)	• Not reported
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback?	Real-time electronic patient-reported outcome measures of quality indicators for sarcoma care are a precise and effective way to capture quality indicators for sarcoma care, which can enable data sharing and predictive modelling (39) • This study looked at the use of real-time reporting of patient-reported outcome measures to evaluate standardized quality indicators for sarcoma care		*Publication date:* 22 December 2022 *Jurisdiction studied:* Spain *Methods used:*	• None reported

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
○ Self-reported survey • By whom is real-time feedback used? ○ Researchers • For what purpose is real-time feedback collected? ○ To support research efforts			Delphi	
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic • For which sectors is real-time feedback collected? ○ Speciality care ▪ Surgical services • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals • By whom is real-time feedback used? ○ Patients and clinicians • 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 • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience	Patient Reported Outcomes Measurement Information System (PROMIS) computer adaptive tests (CATs) is an effective way to assess cancer-related symptoms and communicate results through electronic health record integration to clinical team in real-time (40) • 636 women completed the clinical assessments (which assessed for fatigue, pain, physical function, anxiety, and depression) through patient communication portals • Real-time feedback was provided to clinicians through electronic health record messages; this facilitated the patient referral process for psychosocial and supportive care	Low	*Publication date:* 2014 *Jurisdiction studied:* U.S. *Methods used:* Quantitative	• None identified
• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Specialty care ▪ Surgical services • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey	M-health measurement of patient-reported outcomes after surgery must be patient focused, easy to use, and non-tedious in order to collect the most accurate and relevant data (41) • Recall and response biases are challenges for m-health monitoring of PROs; the authors claim that platforms that have a simple and easy to use design may aid in the reduction of these biases and might increase uniformity in reporting outcomes • The article suggests that m-health measurement platforms for PROs should be specific to the surgery that a patient has undergone to have the most accurate responses	Low	*Publication date:* 21 September 2019 *Jurisdiction studied:* Netherlands *Methods used:* App design	• None

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations

• How is feedback collected?
  ○ Patient portals
  ○ Patient's own technology (e.g., computers, tablets, smartphones)				

Appendix 5a: Detailed jurisdictional scan of the use and implementation of real-time patient feedback programs in other countries

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

Australia	Australian Commission on Safety and Quality in Health Care	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		  ○ Patient-reported outcome measures
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		  ▪ Hospital inpatient
		  ▪ Surgical services
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ Patient portals
		  ○ Healthcare clinic or hospital technology (e.g., computers, tablets)
		  ○ Patient's own technology (e.g., computers, tablets, smartphones)
			• The Australian Commission on Safety and Quality in Health Care released an environmental scan in 2016 that documented how patient-reported outcome measures were being used and implemented across organizations in Australia
			  ○ The report found that many organizations were interested in patient-reported outcome measures (PROMs) but the actual development and implementation was inconsistent
			  ○ Some organizations already developed processes to integrate the collection of PROMs in their existing infrastructures or initiatives, such as patient experience surveys
			  ○ The most frequently engaged organizations were academic institutions and research centres in collaboration with clinical staff and clinical registries
			  ○ There are consortia that support the development of the measures such as the Australian Mental Health Outcomes and Classification Network, the Palliative Care Outcomes Collaboration, the electronic Persistent Pain Outcomes Collaboration, and the Australasian Rehabilitation Outcomes Centre, which often provide patient outcome reports every six months that allows for benchmarking and comparisons to other jurisdictions
			  ○ New South Wales is a leading public sector agency where they have developed small scale collection of PROMs
			• Overall, there has been no consistent approach nationally with each state determining their own practice, where generic measures are more commonly used compared to disease or condition-specific measures

	New South Wales Agency for Clinical Innovation	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		  ○ Patient-reported outcome measures
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		  ▪ Hospital inpatient
		  ▪ Surgical services
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ Patient portals
			• The New South Wales Agency for Clinical Innovation published a rapid scoping review report on patient-reported outcomes and patient-reported experience measures, where they found that automation and real-time feedback is an appealing avenue given its ability to provide real-time insights on quality and safety of care

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Healthcare clinic or hospital technology (e.g., computers, tablets) ○ Patient's own technology (e.g., computers, tablets, smartphones)	
	PRMs – Patient Reported Measures	• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals ○ Healthcare clinic or hospital technology (e.g., computers, tablets) ○ Patient's own technology (e.g., computers, tablets, smartphones)	• South Australia implemented a standardized approach to collect, analyze, and report on PROMs and PREMs to clinicians, which uses the Clinician ZEDOC online platform to ensure real-time digital collection and reporting
	Health Outcomes and Patient Experience (HOPE)	• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals	• New South Wales (N.S.W.) 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 ○ These can be collected by computers, tablet devices, or smartphones at point of care • The system has operability with the N.S.W.electronic medical record and clinical systems, with the ability to analyze and summarize feedback from multiple sources

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Healthcare clinic or hospital technology (e.g., computers, tablets) ○ Patient's own technology (e.g., computers, tablets, smartphones)	
Italy	Italian PRO4All Project	• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level	• The PRO4ALL working group, established in 2021 and comprising various Italian medical associations and patient organizations (e.g., Associazione Italiana Oncologia Medica (AIOM), Associazione Italiana di Miologia (AIM), Associazione Italiana Sclerosi Multipla (AISM), Federazione Italiana delle Associazioni di Volontariato in Oncologia (FAVO), Federazione dei Gruppi Cooperativi Oncologici Italiani (FICOG), Società Italiana di Neurologia (SIN), Federazione Italiana Malattie Rare(UNIAMO)) aims to understand the role of patient-reported outcomes (PROs) in clinical research and regulatory pathways • This PROs, measured through PROMs, capture data directly from patients about their health status, functioning, and quality of life without interpretation by clinicians • One study conducted in Italy covers a wide range of PROMs in oncology
	Electronic patient-reported outcomes measures (ePROMs)	• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level • How is feedback collected? ○ Healthcare clinic or hospital technology (e.g., computers, tablets)	• In 2022, the European Society for Medical Oncology (ESMO) recommended adopting electronic patient-reported outcome measures (ePROMs) in routine clinical practice for cancer patients • The Italian questionnaire consisted of two parts: seven questions on patient characteristics and eight questions assessing satisfaction with current symptom reporting methods and potential implementation of ePROMs in oncology practice • An Italian study found that while patients are generally satisfied with current symptom monitoring methods using verbal and paper-based questionnaires, a large majority (82%) also support implementing ePROMs in routine cancer care and a minority of respondents expressing concerns about technology use and privacy
New Zealand	Mārama Real-Time Feedback (Mārama RTF)	• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures • For which sectors is real-time feedback collected? ○ Speciality care • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected?	• Mārama Real-Time Feedback (Mārama RTF) is a consumer survey for tāngata whai ora and whānau to provide feedback on mental health and addiction services (e.g., respect, communication, family involvement) ○ It helps improve service quality and engagement • The survey uses a Likert scale to ask about respect, involvement in decision-making, communication, family involvement, support for recovery, and recommendations, with a free-text option for additional comments ○ It also collects demographic data (e.g., age, gender, ethnicity) • Mārama RTF questions are available in several languages • National report cards were issued until April 2023, when changes in funding led to the survey's national discontinuation ○ Reach Aotearoa provides ongoing technical support for service-level data collection

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Patient portals ○ Paper and pen ○ Healthcare clinic or hospital technology (e.g., computers, tablets) • 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 organizational level • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	• The survey was successfully implemented by multiple services before its national discontinuation on 31 March 2023
	Te Tāhū Hauora Patient-reported measures	• What real-time feedback is collected? ○ Patient-reported experience measures ○ Patient-reported outcome measures • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level ○ To inform health services planning at the organizational level	• Te Tāhū Hauora collects patient-reported measures through validated and standardized surveys, categorized into PREMs and PROMs ○ PREMs assess feedback on the patient's experience with health services (e.g., what worked well, areas needing improvement), while PROMs focus on aspects of the patient's own health and well-being • Patient feedback is a key measure in assessing progress against health policy objectives outlined in documents like the Interim Government Policy Statement on Health 2022–2024, Te Pae Tata Interim New Zealand Health Plan 2022, and Whakamaua: Māori Health Action Plan 2020–2025
	Te Tāhū Hauora National patient experience surveys	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Primary care ○ Speciality care ▪ Hospital inpatient • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback?	• The national patient experience surveys in Aotearoa New Zealand are a major public survey program designed to gather feedback on healthcare quality • These surveys aim to identify strengths and areas for improvement in patient experiences with healthcare services • Every three months, a national sample of adult hospital and primary care patients is invited to participate, while children under 15 are excluded • Participation is voluntary and anonymous • The program includes three main surveys: the adult primary care patient experience survey, the adult hospital inpatient experience survey, and the adult hospital outpatient experience survey • An additional survey was conducted in July 2020 to assess experiences of care during the COVID-19 pandemic

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Self-reported survey • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level ○ To inform health services planning at the organizational level	• The surveys assess various aspects of patient experience (e.g., communication, partnership, physical and emotional needs, cultural safety, and access to care) • The collected feedback is used to enhance care quality, patient safety, and service access, and to benchmark experiences (i.e., across local, regional, and national levels)
United Kingdom (U.K.)	National PROMs program	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Speciality care ▪ Surgical services • When is real-time feedback collected? ○ During a clinical encounter ○ Immediately following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level ○ To inform health services planning at the system level • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	• PROMs assess the quality of care delivered to NHS patients from their perspective, focusing on specific procedures (e.g., hip and knee replacements) • Data has been collected since April 2009 from all NHS-funded care providers, using pre- and post-operative surveys to measure patients' health status and quality of life (i.e., before and after treatment) • PROMs data are published biannually, with finalised annual data now released in February instead of August to provide more timely information • The measures evaluate health gains by comparing patients' conditions before and after surgical treatment through standardized questionnaires • To enhance the value of PROMs data, they are routinely linked with Hospital Episode Statistics (HES) episode-level information (e.g., patient treatment episodes) ○ In 2021, changes were made to the HES data processing and fields, affecting the PROMs-HES linkage methodology ○ The linkage process includes four stages: patient matching, provider matching, date matching, and a 'tie-break' to select the best match if multiple episode matches occur ○ Changes were made only to the patient matching stage, where the identifier was updated to the Master Person Service (MPS) person identifier (Person_ID) ○ The delay in updating the linkage methodology extended the development and assurance process, impacting the timeliness of PROMs publications
	NHS Friends and Family Test (FFT)	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Home and community care ○ Primary care ○ Speciality care	• The NHS Friends and Family Test (FFT) provides a quick and anonymous way for patients to give feedback on NHS services (e.g., community care, hospitals, mental health services), which helps service providers and commissioners understand patient satisfaction and identify areas for improvement • Since its launch in 2013, the FFT has been widely used across various NHS settings (i.e., GP and dental practices, maternity services, emergency care) ○ Patients can provide feedback after treatment or discharge, either on-site or via post, text message, phone, or online

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

		• When is real-time feedback collected?
		  ○ During a clinical encounter
		  ○ Immediately following a clinical encounter
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• 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
		• For what purpose is real-time feedback collected?
		  ○ To inform learning and improvement at the organizational level
		  ○ To inform health services planning at the organizational level
			• The FFT allows patients to rate their overall experience from "very good" to "very poor" and add comments for detailed feedback
			  ○ This information is crucial for service providers to understand what is working well and where improvements are needed
			• Feedback forms are generally available at GP and dental practices, and patients can request them if needed (e.g., from the reception desk)

	Patient-reported indicator surveys (PaRIS)	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		  ○ Patient-reported outcome measures
		• For which sectors is real-time feedback collected?
		  ○ Primary care
		  ○ Speciality care
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• For what purpose is real-time feedback collected?
		  ○ To inform learning and improvement at the organizational level
			• PaRIS is an Organisation for Economic Co-operation and Development (OECD) initiative that aims to enhance people-centred healthcare by developing and implementing surveys on patient experiences and outcomes
			• The International Survey of Healthcare Experience (ISHE) is a pilot project within PaRIS, focusing on patients with long-term conditions managed predominantly in primary care in England
			• The ISHE survey collects both PROMs and PREMs, along with background characteristics (e.g., age, ethnicity, types of conditions) for data analysis
			• In addition to a patient questionnaire, the survey also includes a provider questionnaire to assess the resources available to primary care providers for managing long-term conditions
			• The results will help understand healthcare service provision in England and enable comparisons with services in other countries

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ To inform health services planning at the system level	
	NHS Patient Survey Programme	• What real-time feedback is collected? ○ Patient-reported experience measures • By whom is real-time feedback used? ○ Organizational leaders ○ Policymakers and system planners • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the organizational level ○ To inform health services planning at the system level	• The NHS Patient Survey Programme is managed by the Care Quality Commission on behalf of NHS England and the Department of Health and Social Care • All eligible NHS trusts in England participate in the NHS Patient Survey Programme, which collects patient feedback on recent healthcare experiences • The Care Quality Commission uses these survey results to measure and monitor performance at both local and national levels
United States (U.S.)	Centers for Medicare & Medicaid Services (CMS) Hospital Quality Reporting (HQR) platform	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Primary care ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ 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 • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making	• As part of their efforts to modernize the HQR system, CMS made reports available for download in real-time, allowing immediate analysis of file accuracy and performance comparison at facility, state, and national levels • The reports include hospital inpatient, hospital outpatient, and inpatient psychiatric facility quality reporting, as well as other quality reporting programs that include patients' perspectives of care

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ 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	
	Integrating standardized electronic collection of patient-reported outcomes with electronic health records	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic ▪ Condition-specific • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Patients and clinicians ○ Organizational leaders • 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 • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Patient experience • Implementation of real-time feedback programs	• The Agency for Healthcare Research and Quality funded an initiative in 2018 to support standardized collection of patient-reported outcomes through patient electronic assessment and integration with electronic health records • Mobile applications developed with standards can allow smoother integration into electronic health records or other IT systems, while better informing clinical management, shared decision making, patient self-management support, and goal setting and attainment • Lessons learned from the project revealed ○ mobile apps help improve survey uptake and completion by patients ○ technical assistance and/or additional staffing is a critical success factor to ensure adoption ○ planning cannot replace 'real-world' testing and adaptation ○ an abstraction layer between the app and EHR is necessary to successfully integrate patient-reported outcome data into the EHR ○ institutional policies impact successful uptake

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Barriers to implementation ○ Facilitators to implementation	
	Integrating Patient-Reported Outcomes into Practice: Benefits, Challenges, and Recommendations for Action	• What real-time feedback is collected? ○ 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 • When is real-time feedback collected? ○ During a clinical encounter ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ 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	• The Agency for Healthcare Research and Quality hosted a national webinar about integrating patient-reported outcomes into clinical encounters, workflows, and electronic health records • The webinar highlights the challenges of spreading and scaling infrastructure to support full-scale implementation • Toolkits supporting workflows for collecting PROs for rheumatoid arthritis were provided to help enhance the uptake of real-time PRO reporting, integration, and analysis • Other facilitators included a culture of continuous improvement within the unit or organization in which the real-time patient feedback program was being implemented • Barriers identified included the need for customization to fit individual unit's and organization's needs and interfacing with electronic medical records, highlighting the need for the development of supportive EHR software to better extract PROs from structured EHR data • Other barriers included the resource intensity of using methods such as natural language processing to extract PROs from clinical notes and the ongoing education and mentorship necessary to support the use of PROs effectively in clinical practice • Key lessons learned shared during the webinar include 1) professional consensus on which measures are valid, reliable, and feasible in clinical practice facilitated a cohesive national PRO collection strategy; 2) the development and endorsement of quality measures incentivized participation by rheumatologists; and 3) technology infrastructure hosting the registry where PROs were stored facilitated performance feedback, research, and quality improvement • Other experiences from the implementation of real-time feedback in community pharmacies highlighted the lack of existing integrations among technology vendors and concerns about feasibility and effectiveness of future integrations, and the resistance of some sub-groups of patients who continue to prefer paper over electronic-based surveys • Recommendations to mitigate these challenges included working with pharmacists to increase engagement and buy-in about the potential benefits of electronic PRO collection, and a toolkit for pilot implementation was developed to support its uptake • Experiences from another pilot project for hip and knee arthroplasty found that 1) text messaging can improve response rates to PROMs surveys, 2) patients prefer personalized PROMs over standardized orthopedic PROMs to track progress, 3) personalized PROMs are better collected by open-ended questions and change overtime, and 4) providing surgeons with their performance PROMs and cost outcomes did not improve these outcomes (distrust in data and relatively weak intervention were likely contributing factors) • Overall, the collection of PROMs is being accelerated by CMS policies, and standardized PROMs play a role for aggregate reporting and comparisons, but patients are more focused on personal outcomes • Additionally, there is strong interest and opportunity in using PROMs to enhance individual care and shared decision-making

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ To inform learning and improvement at the organizational level ○ To inform learning and improvement 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? ○ Patient experience ○ Provider experience ○ Costs • Implementation of real-time feedback programs ○ Barriers to implementation ○ Facilitators to implementation	
	Advancing the Collection and Use of Patient-Reported Outcomes through Health Information Technology	• What real-time feedback is collected? ○ 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 • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ 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	• The U.S. Department of Health and Human Services' Office of the National Coordinator for Health Information Technology commissioned a report on advancing PROs through health information technology • A PRO Fast Healthcare Interoperability Resources (FHIR) implementation guide was developed to support standardized data exchange • Application programming interfaces (APIs) were used to provide guidance for collecting, exchanging, and integrating PRO data between health IT systems in real time • These efforts are thought to enhance patient-provider relationships and support patient-centred outcome research by better managing PRO data • Ongoing efforts to build a comprehensive health IT ecosystem with PROs will help support PRO collection and use in real-time through interoperable systems • The report highlights the need for FHIR standard refinement and standardized APIs and health measurement instruments to help ensure that PRO data can be shared seamlessly across systems • Education and outreach was also identified as a crucial success factor, highlighting the need to increase awareness among providers and patients about the benefits of PROs

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ 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 support research efforts • Implementation of real-time feedback programs ○ Facilitators to implementation	
	Intermountain Healthcare + Notable Health's My Health+ Digital Platform	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • When is real-time feedback collected? ○ During a clinical encounter ○ Immediately following a clinical encounter ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals ○ Patient's own technology (e.g., computers, tablets, smartphones)	• Intermountain Healthcare, in partnership with Notable Health, developed an automated and digital platform to facilitate patient uptake and post-visit follow-up (including PROMs) • The platform also can automatically provide patients with intelligent questionnaires after their visit and collect PROM data that is uploaded to their EHR in real-time, allowing clinicians to follow a patient's trajectory and make adjustments to care • Mobile registration and integration with the My Health+ patient portal app with digital assistants are used along with automated clinical documentation and data imputation into EHRs • Questionnaires are customizable for individual medical histories and PROM collection • Initial program evaluations found a decrease in check-in time by 25%, a 94% satisfaction rating for digital check-in, 30 minutes of time saved per day for medical assistants, and greater patient engagement • The portal plans to expand across providers and specialities

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

		• By whom is real-time feedback used?
		  ○ Patients and clinicians
		  ○ Organizational leaders
		• 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
		• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
		  ○ Patient experience
		  ○ Provider experience
		  ○ Costs	

	Kaiser Permanente feedback-informed care (FIC) for mental healthcare services	• What real-time feedback is collected?
		  ○ Patient-reported outcome measures
		  ▪ Generic
		  ▪ Condition-specific
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		• When is real-time feedback collected?
		  ○ During 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's own technology (e.g., computers, tablets, smartphones)
			• Kaiser Permanente's feedback-informed care (FIC) 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
			• At the system level, aggregated data helps refine treatment approaches and improve quality of care
			• Electronic questionnaires are provided to patients prior to their visit and help to track patient progress overtime, improving the therapeutic relationship and enabling the provider to see how the patient responds to changes over time
			• The report highlights the need for training, as clinicians need to be able to use ePRO tools and interpret the data effectively
			• Additional considerations include the need for systems to be adaptable to support in-person and virtual care environments, ensuring data security within health information systems, and creating regular updates and feedback loops to ensure the data is used regularly

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

		• By whom is real-time feedback used?
		  ○ Patients and clinicians
		  ○ Organizational leaders
		  ○ Policymakers and system planners
		• 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
		• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
		  ○ Health outcomes
		  ○ Patient experience
		  ○ Provider experience
		• Implementation of real-time feedback programs
		  ○ Barriers to implementation
		  ○ Facilitators to implementation	

Appendix 5b: Detailed jurisdictional scan of the use and implementation of real-time patient feedback programs in Canadian provinces and territories

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

Pan-Canada	Data Collection Manual: Hip and Knee Arthroplasty	• 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?
		  ○ Speciality care
		  ▪ Surgical services
		• When is real-time feedback collected?
		  ○ Multiple times
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ 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
		  ○ Researchers
		• For what purpose is real-time feedback collected?
		  ○ To inform care decisions
		  ○ To inform learning and improvement at the system level
		• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
		  ○ Patient experience
		  ○ Provider experience
		  ○ Costs
			• The Canadian Institute for Health Information (CIHI) provides a manual supporting the collection of data for hip and knee arthroplasty, which encourages electronic collection of patient-reported outcome measures (PROMs) surveys over paper or via telephone interview
			• Recommended instruments include the Oxford Hip Score and Oxford Knee Score as condition specific instruments, as well as the EQ-5D-5L as generic alternatives
			• The manual suggests that the use of web forms and mobile apps have the potential to reduce data collection burden for staff and patients, which can in turn lead to higher response rates and improved data
			• PROMs can be used to inform care and clinical decision-making and can be accessed for research purposes at proms@cihi.ca
			• Electronic collection of PROMs can also enable real-time PROMs reports to inform care and treatment decisions
			• The manual recommends collecting comparative PROMs both pre-surgery (within eight weeks of surgery) and at one year post surgery (nine to 15 months after)
			• CIHI also maintains that patient-reported experience measures (PREMs) and PROMs play an important role for achieving health system goals

British Columbia	The Dynamic Analysis and Reporting Tool (The DART)	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		  ○ Patient-reported outcome measures
		• For which sectors is real-time feedback collected?
		  ○ Primary care
		  ○ Speciality care
		  ▪ Hospital inpatient
			• The British Columbia Patient-Centred Measurement Steering Committee developed the Dynamic Analysis and Reporting Tool (the DART), an online platform providing 24/7 access to patient feedback about safety and quality of healthcare
			• The results are analyzed in 'close to real time' and reflect the experiences and health-related quality of life of patients through aggregate, de-identified results at unit, facility, health authority, and provincial levels

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		▪ Surgical services ○ Long-term care • When is real-time feedback collected? ○ During a clinical encounter ○ Immediately following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ 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 • For what purpose is real-time feedback collected? ○ 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	○ The results are used to identify areas for improvement in patient experiences • The DART was created for clinicians, leaders, policymakers, and the general public • The Comment Analysis Toolkit for Patient eXperiences (CAT-PX) can be used to help review patient experience qualitative data using natural language processing • The data is said to help the province achieve its strategic objective of measuring patient experiences and outcomes and progressing towards patient-centred care • The tool aims to enhance public accountability and support continuous improvement of patient outcomes and experiences across sectors, including inpatient acute care, emergency department care, cancer care, mental health and substance use care, long-term residential care, and surgical pre- and post-op care • The time at which patients provide survey responses in relation to their care experiences was not specified, suggesting it may vary across units and organizations implementing DART ○ However, examples given about DART's implementation suggest that surveys were provided during a clinical encounter or shortly following a clinical encounter
	Fraser Health Real-Time Experience Survey	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Home and community care ○ Primary care ○ Speciality care ▪ Hospital inpatient ▪ Surgical services ○ Long-term care ○ Public health • When is real-time feedback collected? ○ During a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Healthcare clinic or hospital technology (e.g., computers, tablets) • By whom is real-time feedback used? ○ Patients and clinicians	• The Fraser Health Authority partnered with the Regional Patient Advisory Council (PAC) developed a quick electronic survey patients complete during care about their experience, enabling managers to access real-time data 24/7 at unit level • Data gathered through the survey is immediately actioned for service recovery, and can inform ongoing quality improvement at unite and site levels • Patients have reported feeling their feedback is valued and appreciate the opportunity to improve services

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Organizational leaders ○ Policymakers and system planners • For what purpose is real-time feedback collected? ○ 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 • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Patient experience	
Alberta	None identified		
Manitoba	Hip and Knee Replacement Surgery	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Surgical services • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Paper and pen • By whom is real-time feedback used? ○ Policymakers and system planners • For what purpose is real-time feedback collected? ○ To inform care decisions ○ To inform learning and improvement at the system level ○ To inform health services planning at the system level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience ○ Costs	• As of September 2020, Manitoba operates four provincial initiatives to collect PROMs, one of which is targeted towards patients undergoing hip and knee joint replacement surgery ○ The PROMs tool used consists of the EQ-5D-5L (generic) and the Oxford Hip Score and Oxford Knee Score (condition-specific) ○ Additional intraoperative information is collected regarding the diagnosis, surgical technique and implant details, and self-reported data regarding complications and overall patient satisfaction ○ The data is preoperatively collected in the clinic and then one-year post-operatively via mail (as a paper-based survey); this information is stored in the Manitoba Joint Replacement Registry and is reviewed by regional quality and standards committees ○ This initiative has helped to provide a more holistic understanding of patient outcomes post-surgery and is an assessment to support the delivery of care within the province
	Spine Surgery	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic ▪ Condition-specific • For which sectors is real-time feedback collected?	• As of September 2020, Manitoba operates four provincial initiatives to collect PROMs, one of which is targeted towards patients undergoing spinal surgery (with the exception of traumatic spinal cord injuries as that data is collected by the Rick Hansen Spinal Cord Injury Registry (RHSCIR))

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Speciality care ▪ Surgical services • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Paper and pen • By whom is real-time feedback used? ○ Organizational leaders ○ 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 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	○ The PROMs tool used consists of the SF-12 Quality of Life questionnaire, EuroQol (EQ-5D), PHQ-9, Neck Disability Index, or the Oswestry Disability Index ○ Additional information is collected regarding the initial assessment from the surgeon, surgical procedure, and discharge information, and documenting any adverse events ○ The data is collected multiple times, including pre-operatively and post-operatively at three months, 12 months, two years, five years, and 10 years through a paper-based survey that is then directly entered into an internet database; this information is stored in the national registry with the Canadian Spine Society (who reports performance on an annual basis) • This initiative helps to ensure clinical best practices; resource utilization and acquisition are in the best interest of patient care and support effective comparative reporting, tracking of patterns, and quality improvement
	Cataract Surgery	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care ▪ Surgical services • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • For what purpose is real-time feedback collected? ○ To inform learning and improvement at the system level ○ To inform health services planning at the system level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes	• As of September 2020, Manitoba operates four provincial initiatives to collect PROMs, one of which is targeted towards patients undergoing cataract surgeries ○ The PROMs tool used is the Visual Function Index Questionnaire (VF-14) ○ Additional information is collected regarding the wait time length for surgery, work impairments and driving impairments, and the potential loss of a driver's licence ○ The data is preoperatively collected through a questionnaire administered via telephone and then one-year post-operatively; this information is stored in the Manitoba Cataract Waiting List Program • This initiative has helped to improve surgical wait times for cataracts across the province

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		• Patient experience	

	Cancer/CancerCare Manitoba	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		  ○ Patient-reported outcome measures
		  ▪ Condition-specific
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		  ▪ Hospital inpatient
		• When is real-time feedback collected?
		  ○ During a clinical encounter
		  ○ Multiple times
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ Paper and pen
		• By whom is real-time feedback used?
		  ○ Organizational leaders
		  ○ 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 organizational level
		  ○ To inform learning and improvement at the system 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
			• As of September 2020, Manitoba operates four provincial initiatives to collect PROMs, one of which is targeted towards cancer patients
			  ○ The PROMs tool used include the Comprehensive Problem and Symptom Screening (COMPASS) Questionnaire with the Canadian Problem Checklist and Edmonton Symptom Assessment System-revised (ESAS-r)
			  ○ Additional information is collected regarding the patient's medication use and past medical history
			  ○ The data collected at each clinical visit through a paper-based survey is directly entered into their CancerCare Manitoba patient electronic medical records
			  ○ This initiative helps to inform day-to-day care and targeted interventions for the patient, such as psychosocial, smoking cessation, or symptom management efforts
			• CancerCare Manitoba: My Cancer Experience utilizes the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) as a patient-reported experience measure

	Outpatient Shoulder and Knee Surgery (Pan Am Clinic – regional)	• What real-time feedback is collected?
		  ○ Patient-reported outcome measures
		  ▪ Generic
		  ▪ Condition-specific
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		  ▪ Surgical services
		• When is real-time feedback collected?
		  ○ Multiple times
		• What methodological approach is used to collect feedback?
			• As of September 2020, Manitoba operates one regional initiative to collect PROMs for patients undergoing shoulder and knee-related outpatient surgeries in the Pan Am orthopedic clinic in Winnipeg
			  ○ The PROMs tool used consist of:
			  ▪ generic: EQ-5D-5L
			  ▪ condition-specific for knee: International Knee Documentation Committee (IKDC) subjective evaluation, MARX activity rating scale, Tegner activity scale, and SANE score
			  ▪ condition-specific for shoulder: the American Shoulder and Elbow Surgeons Standardized Shoulder Assessment Form (ASES), SANE

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Self-reported survey • How is feedback collected? ○ Paper and pen • 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 organizational level ○ To inform health services planning at the organizational 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	score, Western Ontario Rotator Cuff index (WORC), or Western Ontario Shoulder Instability Index (WOSI) ○ Additional information is collected regarding the demographics, work status, and post-operative surgical complications ○ The data is preoperatively collected in the clinic and then post-operatively at three months, six months, nine months, and 12 months through a paper-based survey • This initiative has helped to provide a more holistic understanding of patient outcomes post-surgery and is an assessment to support the delivery of care within the province
	Inpatient Hospital Survey	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Speciality care ▪ Hospital inpatient • When is real-time feedback collected? ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Paper and pen ○ Patient's own technology (e.g., computers, tablets, smartphones) • By whom is real-time feedback used? ○ Policymakers and system planners • For what purpose is real-time feedback collected? ○ To inform care decisions ○ To inform learning and improvement at the system level ○ To inform health services planning at the system level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes • Patient experience	• As of September 2020, Manitoba Shared Health operates one provincial initiative to collect PREMs for patients discharged from Manitoba hospitals who had at least one overnight stay ○ The PREM tool used is the Canadian Patient Experience Survey for inpatient care ○ Additional information is collected regarding patient safety and the use of services in other languages (including French) ○ A random sample of discharged patients is mailed a paper-based survey (or provided with the ability to complete the survey online); responses are saved in the Manitoba Health Services Commission and Canadian Institute for Health Information databases ○ Performance reporting is conducted on a monthly basis on the province's management dashboard and then in six months and 12 months reports are sent to regional health authorities; this initiative helps to inform quality improvement initiatives • Manitoba Health set a target of having 72% of their survey participants rating their overall hospital experience as a 9/10 on the Canadian Patient Experience Survey for inpatient care
	Emergency Department Survey (regional)	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Speciality care	• As of September 2020, Manitoba operates one regional initiative to collect PREMs for patients who visited urgent care and/or emergency departments (EDs) in the Winnipeg Regional Health Authority

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

		• When is real-time feedback collected?
		  ○ Hours or days following a clinical encounter
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ Paper and pen
		  ○ Patient's own technology (e.g., computers, tablets, smartphones)
		• By whom is real-time feedback used?
		  ○ Organizational leaders
		• 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 organizational level
		  ○ To inform health services planning at the organizational level
		• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
		  ○ Health outcomes
		• Patient experience
			○ The PREM tool used is the Urgent Care and ED Survey (WRHA Service Experience Survey)
			○ Additional information is collected regarding patient's health background and level of education
			○ A random sample of discharged patients from the Winnipeg Regional Health Authority is mailed a paper-based survey (or provided with the ability to complete the survey online)
			○ Performance reporting is conducted on a quarterly basis, with the data available on the Winnipeg Regional Health Authority's Regional Patient Engagement SharePoint page; this initiative helps to inform quality improvement initiatives

	Prairie Mountain Health	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ Patient's own technology (e.g., computers, tablets, smartphones)
		• By whom is real-time feedback used?
		  ○ Organizational leaders
		• 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 organizational level
		  ○ To inform health services planning at the organizational level
		• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
		  ○ Health outcomes
		• Patient experience
			• Prairie Mountain Health uses the Client Experience Questionnaires (CEQ) to obtain feedback from patients who have had overnight stays in the hospital
			  ○ The online questionnaire assesses the values of dignity, respect, trust, information sharing, participation, accessibility, responsiveness, and quality
			  ○ The questionnaire ensure that patients are involved in the care they receive and to support quality improvement initiatives; results are reported quarterly
			• On 4 April 2024, the last quarterly results were reported (with a total of 6,517 surveys), with findings indicating:
			  ○ 71.5% of respondents always or strongly agree to being treated with respect, trust, and dignity
			  ○ 78.5 of respondents always or strongly agree to having staff discuss healthcare options with them and ensuring they were given the necessary information to make an informed decision regarding their health
			  ○ 80.8% of respondents always or strongly agreed to participating in decision-making regarding their own care and/or encouraged to take part/have their choices respected
			  ○ 67.3% of respondents always or strongly agreed to having their care being coordinated in a timely manner
			  ○ 72.1% of respondents always or strongly agreed to having staff who were qualified to perform their tasks and were satisfied with the quality of care received

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

	Cardiac Rehabilitation	• What real-time feedback is collected?
		  ○ Patient-reported outcome measures
		  ▪ Generic
		• For which sectors is real-time feedback collected?
		  ○ Rehabilitation care
		• When is real-time feedback collected?
		  ○ Multiple times
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		• By whom is real-time feedback used?
		  ○ Organizational leaders
		• 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 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
			• The Cardiac Rehabilitation program uses the Brief Symptom Inventory (BSI), Duke Activity Status Index, and the Short Form 36 (SF-36) Health Survey as PROM tools
			• In the 2019–2020 Annual Report for the Cardiac Rehabilitation Program, six indicators were selected to track program efficiency and participant benefit; PROM tools selected for two of them were to measure psychological well-being and risk for depression (BSI) and quality of life (SF-36 Health Survey)
			  ○ Participants reported pre- and post-participation data to assess overall improvement in participants

Saskatchewan	Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs)	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		  ○ Patient-reported outcome measures
		• For what purpose is real-time feedback collected?
		  ○ To inform learning and improvement at the system level
			• The Saskatchewan Health Quality Council is partnering with Saskatchewan Health Authorities to implement patient-reported experience and outcome measures (PREMs/PROMs), aiming to incorporate patient perspectives into healthcare system improvements and decision-making processes
			• The Saskatchewan Centre for Patient-Oriented Research (SCPOR) and Saskatchewan Health Quality Council held workshops focused on creating an understanding of Learning Health Systems (LHS)
			• These sessions explored how PROMs and PREMs can contribute to patient-centred care in an LHS, how LHS can be applied to the Saskatchewan context, and why patient engagement is a crucial aspect of their success
			• The Saskatchewan Health Quality Council staff created a PREMs & PROMs Survey Creation Tool to guide conversations with teams interested in developing or using standardized PROMs or PREMs

Ontario	Norfolk General Hospital Patient Experience Survey	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		  ▪ Hospital inpatient
		• When is real-time feedback collected?
			• Norfolk General Hospital's (NGH) Patient Experience Survey was developed in collaboration with patient and family advisors to provide patients with an accessible way to easily provide feedback to NGH on their patient care experiences
			• Patients can access the survey through QR codes within the hospital, online, or by paper during their hospital visit

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ During a clinical encounter ○ Immediately following a clinical encounter ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey	• Patients are asked to complete the survey within a month of receiving care (it is unclear how soon patients are informed about this survey) • In the survey, participants are asked to indicate: ○ which department they most recently visited (emergency department or an inpatient unit) ○ how staff treated them during their experience ○ how effective the staff's communication was ○ observed infection, prevention, and control measures of hospital staff ○ any difficulties or challenges they experienced
	Ontario Ministry of Health hip and knee PROMs project	• 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? ○ Speciality care ▪ Hospital inpatient ▪ Surgical services • When is real-time feedback collected? ○ During a clinical encounter ○ Immediately following a clinical encounter ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Healthcare clinic or hospital technology ○ Patient's own technology • By whom is real-time feedback used? ○ Patients and clinicians ○ Organizational leaders ○ Policymakers and system planners • 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	• The Ontario Ministry of Health (the ministry) began collecting PROMs in hospitals in 2017 and implemented a pilot project specifically focused on collecting PROMs data on hip and knee replacement surgery using the collection of the generic survey (EQ-5D-5L) and the Oxford hip/knee scores (condition-specific) ○ The pilot project is being carried out through a collaboration between the ministry, Ontario Health (OH), Cancer Care Ontario, and the CIHI • To collect the PROMs data, OH developed the Integrated Symptom Assessment and Collection (ISAAC) platform that can be accessed electronically using mobile devices or kiosks and can automatically pull data from completed PROMs and send it to OH ○ PROMs data flows directly into the ISAAC platform in real time where physicians are able to access the data and reports can automatically be generated to measure PROM uptake and compare response trends over time at the local, provincial, and national levels ○ The ministry aims to collect PREMs in the same manner as PROMs • Additional funding is not provided to hospital sites participating in the pilot project; however, the ministry of health has committed to providing participating sites with the supports they need (e.g. technological hardware) to facilitate PROMs collection • The PROMs survey can be completed during a patient's pre-surgical visit, within three to five months after surgery, or within nine to 15 months after surgery ○ The survey is available electronically in English and French and takes about five minutes to complete • It is unclear exactly when patients are asked to complete this survey by hospital staff
	Princess Margaret Cancer Centre	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected?	• The Your Voice Matters Survey is used by the Princess Margaret Cancer Centre to help them understand what is most important to their cancer patients about the care they receive and to improve patient care experiences

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
	Voice Matters Survey	○ Speciality care ▪ Hospital inpatient • When is real-time feedback collected? ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology • By whom is real-time feedback used? ○ Organizational leaders ○ Policymakers and system planners • 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 • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? • Patient experience	○ The survey is sent by email to patients two days after their appointment at the cancer centre and includes multiple-choice questions and an open text box for feedback ○ The survey remains open for 10 days and takes approximately five minutes • After reviewing patient feedback from the survey, the hospitals' Patient and Family Experience Committee developed five main priorities: ○ reduce wait times ○ address patients' emotional worries and concerns ○ spend sufficient meaningful time with patients ○ involve patients more in decisions about their care ○ relate to patients beyond their diagnosis • Changes made by the hospital as a result of patient feedback from the survey included improved signage both inside and outside of the hospital, improved support for using the patient portal, and enhanced structural resources, such as seating and patient monitors • Data from the Your Voice Matters Survey is also sent to Ontario Health to inform quality improvement across the province
	Grand River Hospital patient experience survey	• What real-time feedback is collected? ○ Patient-reported experience measures • For which sectors is real-time feedback collected? ○ Primary care ○ Rehabilitation care • When is real-time feedback collected? ○ Hours or days following a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient's own technology • By whom is real-time feedback used? ○ Patients and clinicians ○ Organizational leaders • For what purpose is real-time feedback collected? ○ To inform care decisions ○ To inform learning and improvement at the organizational level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? • Patient experience	• Grand River Hospital introduced a digital format of their patient experience survey in select outpatient clinics in September 2023 where patients receiving care in their outpatient clinics received a patient survey by email three to 10 days following discharge ○ At the time, the hospital intended to move to email distribution of surveys in adult inpatient and pediatric programs in the future • In alignment with its strategic goals, the hospital aimed to use the patient experience data to inform their organizational changes

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program

	Ontario Hospital Association recommended short-form surveys	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		  ▪ Hospital inpatient
		  ○ Rehabilitation care
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
			• The Ontario Hospital Association has produced several short-form patient experience survey tools for hospital staff and patients to use with electronic platforms, including the Ontario Adult Inpatient short-form patient experience survey and the Ontario Outpatient Experience Survey

Quebec	Patient Reported Outcomes Measurement Information System (PROMIS) Canada	• What real-time feedback is collected?
		  ○ Patient-reported outcome measures
		  ▪ Generic
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• How is feedback collected?
		  ○ Paper and pen
		  ○ Patient's own technology (e.g., computers, tablets, smartphones)
		• By whom is real-time feedback used?
		  ○ Policymakers and system planners
		• 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 system level
		  ○ To inform health services planning at the system level
		• What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim?
		  ○ Health outcomes
		  ○ Patient experience
			• PROMIS is a self- and parent-reported measures of physical, mental, social, and global health for both adults and children of the general population (and those living with a chronic condition)
			• McGill University is undertaking the translation, validation, and adaptation of this program into the French language and for use within Canada
			• The adapted version will feature additional item banks and measures are currently under development for early childhood domains of general health, internalizing/externalizing behaviours, sleep disturbances, physical activity, family and peer relations, and well-being

	Quebec Survey on Quality of Cancer Control Services (Enquête québécoise sur la qualité des services de lutte contre le cancer)	• What real-time feedback is collected?
		  ○ Patient-reported experience measures
		• For which sectors is real-time feedback collected?
		  ○ Speciality care
		• What methodological approach is used to collect feedback?
		  ○ Self-reported survey
		• By whom is real-time feedback used?
		  ○ Policymakers and system planners
		• 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 system level
			• The Quebec Survey on the Quality of Cancer Control Services provides cancer patients aged 18 years or older in Quebec who had received surgical, radiotherapy, or chemotherapy treatment to give feedback on the quality of care they received
			• This survey used the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) as a patient-reported experience measure
			  ○ Real-time patient data was obtained in 2008 and 2013 (five years post implementation of interdisciplinary teams and pivot nurses in oncology)

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ To inform health services planning at the system level • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience	
New Brunswick	SeamlessMD	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience ○ Provider experience	• Horizon Health Network (Horizon), as a member of the Coordinated Accessible National (CAN) Health Network, is initiating a project that will enable both patients and clinicians to utilize SeamlessMD, a top Canadian-developed digital patient journey application • The implementation of the SeamlessMD digital care journey platform will offer essential digital health support to patients preparing for or recovering from cardiac surgery at the New Brunswick Heart Centre, the province's sole tertiary cardiac care centre • Patients undergoing cardiac surgery at the New Brunswick Heart Centre can use the SeamlessMD app on their smartphones, tablets, or computers • The app provides guidance before and after surgery through reminders, evidence-based education, symptom-tracking surveys, and videos, helping them adhere to the care plan set by their care team • Care teams at the New Brunswick Heart Centre will also benefit from this technology, as they will be able to receive alerts, remotely monitor patients, and access analytics to deliver better care • This initiative aligns with Horizon's key priority of enhancing patient experiences, as this digital tool has received highly positive feedback from patients in other healthcare organizations across North America since it enables patients to better track, manage, and stay informed about their healthcare journeys • 35+ clinical studies & evaluations have shown SeamlessMD to improve the patient experience while reducing hospital length of stay, readmissions, and ED visits
Newfoundland and Labrador	None identified		
Nova Scotia	Noona	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Condition-specific • For which sectors is real-time feedback collected? ○ Speciality care • When is real-time feedback collected? ○ Multiple times • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected?	• Noona is a patient-reported outcomes tool that facilitates timely, easy, and ready access to care by electronically connecting the patient receiving radiotherapy to their healthcare provider • Patients will also be able to report their symptoms from home using their phone, tablet, or desktop, giving people more time to reflect on their answers • Reported symptoms will be discussed during the patient's next visit with their cancer care team, who in turn can make more informed recommendations about their care

Jurisdiction	Program	Dimension of the organizing framework that is the focus of the program	Key features, outcomes and implementation considerations of the program
		○ Patient portals • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making ○ To inform care decisions • What are the effects of real-time feedback on supporting the achievement of the equity-centred quadruple aim? ○ Health outcomes ○ Patient experience ○ Provider experience	• Care can consist of early interventions to manage symptoms, identifying psychosocial and emotional needs, or offering digital content to better educate and guide patients through their cancer journey • Noona also responds to a pressing need to move away from paper-based reporting, which can be misplaced as patients manage the complexities of their illness, treatment, and its impacts • The immediate next steps for implementing this platform involve integrating patient-reported outcome measures that are both general to cancer and specific to tumor sites • Noona will facilitate patient-reported outcome assessments both in clinics and remotely, enabling healthcare providers to reach patients who are hard to access, such as those in rural areas or affected by clinic COVID-19 restrictions • There is potential to expand the project's scope in the future to include patients from medical and surgical oncology, in addition to those receiving radiotherapy
Prince Edward Island (P.E.I.)	Electronic Medical Records	• What real-time feedback is collected? ○ Patient-reported outcome measures ▪ Generic • For which sectors is real-time feedback collected? ○ Primary care • When is real-time feedback collected? ○ During a clinical encounter • What methodological approach is used to collect feedback? ○ Self-reported survey • How is feedback collected? ○ Patient portals • By whom is real-time feedback used? ○ Patients and clinicians • For what purpose is real-time feedback collected? ○ To increase patient involvement in decision-making	• P.E.I. is increasingly using an electronic medical record to help patients have full access to their information, communicate with their healthcare team, and provide information • This information can be used to facilitate decision making • This program is not necessarily real time or rapid
Northwest Territories	None identified		
Yukon	None identified		
Nunavut	None identified		

Appendix 6: Documents excluded at the final stage of reviewing

Document type	Hyperlinked title
Single study	Treat-to-target in rheumatoid arthritis: Evaluating the patient perspective using the Patient Opinion Real-Time Anonymous Liaison system: The RA T2T PORTAL study
Single study	The use of patient-reported outcome measures in clinical practice and clinical decision making
Full systematic review	A systematic review of the use of the electronic health record for patient identification, communication, and clinical support in palliative care
Single study	Responding to the tāngata whai ora voice: an Aotearoa New Zealand quality improvement solution
Single study	Estimation of symptom severity during chemotherapy from passively sensed data: Exploratory study
Single study	Symptom screening via screen: Real-time electronic tracking of pediatric patient-reported outcomes
Single study	Automation and simplification: Drivers of innovative collection and use of patient-reported outcomes data
Single study	Improving psychiatric care through integrated digital technologies
Single study	Key methodological considerations for usability testing of electronic patient-reported outcome (ePRO) systems
Single study	A novel application of SMART on FHIR architecture for interoperable and scalable integration of patient-reported outcome data with electronic health records
Single study	Patient-reported outcome measures in multiple myeloma: Real-time reporting to improve care (My-PROMPT) – a pilot randomized controlled trial

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