Ferrari *et al.*
Health Research Policy and Systems (2025) 23:34
https://doi.org/10.1186/s12961-024-01281-w

Health Research Policy
and Systems

RESEARCH **Open Access**

Implementing a rapid-learning health system in early intervention services for psychosis: qualitative evaluation of its feasibility and acceptability

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Abstract

Background Heterogeneity in implementing essential evidence-based early intervention for psychosis services (EIS) components persists despite existing fidelity standards/guidelines in many countries. Rapid-learning health systems (RLHS) may remedy these challenges, improving service delivery through systematic data collection, analysis, feedback and capacity-building activities. SARPEP (*Système Apprenant Rapide pour les Programmes de Premiers Épisodes Psychotiques*) is the first Canadian RLHS for EIS. This paper presents qualitative findings from the mixed-method study that evaluated the feasibility and acceptability of SARPEP.

Methods We conducted six focus groups on the implementation of SARPEP with 25 participants from all SARPEP stakeholder groups; most were involved from project inception and throughout the 3-year implementation. The Reach, Effectiveness, Adoption, Implementation, Maintenance (RE-AIM) framework (Glasgow, et al., 2019) and Lessard's dimensions for learning health systems guided data collection and deductive analysis.

Results Reach: focus group participants reflected SARPEP reach and included all stakeholders involved (six service users, two family members, four psychiatrists, six managers, seven team leaders) who shared their experiences. Effectiveness: participants confirmed that SARPEP improved program capacity for data collection on core indicators and promoted evidence-based practices. Adoption: participants supported the selection of specific indicators and need to improve data-gathering technologies in the RLHS, even while challenges persisted regarding the integration of digital platform use by service users into routine care. Implementation and maintenance: all participants credited the RLHS with enabling mutual learning, self-reflection of programs and shared improvement of practices.

Conclusions SARPEP contributes to promote evidence-based care and a sense of belonging within the Quebec EIS network.

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Introduction

More effective than routine care [1–7], early intervention services (EIS) have become the treatment of choice for psychosis in many countries such as Australia, the United Kingdom, Singapore, Hong Kong, the United States [8], Denmark [9, 10], Canada [11] and elsewhere. International guidelines [1–3, 12, 13] describe key components of EIS such as open referral, timely treatment access, service user and family engagement, appropriate patient–staff ratios, case management and continuous staff development. Team-based care combines pharmacological treatment with evidence-based psychosocial interventions (e.g. cognitive behavioural therapy, CBT).

In Canada, EIS have been implemented for over two decades under provincial jurisdiction, with British Columbia [14], Nova Scotia, Ontario [15] and Quebec [16, 56] leading policy development and creating EIS guidelines and standards. Vibrant EIS networks, such as the EPI APP [17] in British Columbia, EPION [18] in Ontario, AQPPEP [19] in Quebec and the Canadian Consortium for Early Intervention in Psychosis (CCEIP) [20], promote knowledge translation and evidence-based care. Yet, as in other countries [21, 22], EIS implementation in real-life Canadian settings has proven challenging [23–25] in the uptake of certain essential components [26] based on evidence-based practices and provincial quality indicators (e.g. open referral processes; appropriate patient/case manager ratios) [23–25]. Many programs struggle with maintaining fidelity due to variations in training, resource allocation and staff turnover [27, 28], which may compromise the implementation of evidence-based practices [29]. Engagement of service users, another important aspect of EIS, remains challenging, with lower engagement sometimes resulting from lack of family support and involvement in treatment [30].

The rapid-learning health system (RLHS) embeds data collection in clinical settings for real-time, problem-focused learning and continuous quality improvement [31]. The RLHS is “a continuously learning health system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience” [31]. Core principles include commitment to a culture of continuous learning and improvement, stakeholder integration in planning and implementation and care guided by the systematic use of real-time evidence. Using information technology methods, the RLHS captures and analyzes data on care experiences, continually evaluating outcomes and refining processes (e.g. training) while integrating a feedback cycle for learning and improvement [32]. The RLHS promotes innovation and responsiveness [33], bridges evidence and practice and improves efficiency, effectiveness and quality in healthcare delivery [34–39]. Successful implementation of a RLHS in EIS hinges on developing practices that ensure safety, accountability and evidence-based, quality care while fostering engagement, collaboration, appreciation of diverse knowledge and innovation.

While the concepts of learning health system (LHS) and “rapid”-learning health system (RLHS) are closely related in leveraging data generated from routine clinical practice to enhance healthcare quality and outcomes, their primary distinction lies in the immediacy of learning and adaptation in the RLHS. The LHS focuses on continuous learning, adaptation and improvement over time, integrating new knowledge at a measured pace [40, 41], while the RLHS has the same aims but emphasizes rapid cycles of learning and implementation, aiming to translate evidence into practice in almost real time [36]. The United States, United Kingdom, Australia and Canada [42] are currently leading the work on implementation of LHS/RLHS, with most studies focused on patient populations or clinical contexts related to medicine [41, 43]. LHS research has more recently focused on early psychosis services (EIS), known as Coordinated Specialty Care in US services. The US Early Psychosis Intervention Network (EPINET) comprises 100 programs organized under eight academic hubs [44] which are part of a LHS. Different large-scale studies driven by this LHS pinpointed areas to be targeted for improvement of practices such as low EIS program completion rates (20–30%) [44]; while other studies allowed for the monitoring of important patient outcome domains such as reduction of suicide risk [45] and improvement of patient functioning and symptoms over the first year of treatment, and more emergency service use [46]. OnTrack NY, one of the EPINET regional hubs, used the infrastructure development to promote quality improvement in services, support practice-based research and accelerate innovation [8]. The uniqueness and potential of this LHS for advancing research on early psychosis is reflected in the system’s capacity to support longitudinal research on thousands of early intervention patients treated in real-life settings, using the US national repository, the EPINET National Data Coordinating Center, that houses clinical measures, assessment and intervention strategies, as well as de-identified person-level data for all EIS nationwide [47].

Parallelly, in 2019 our research team created SARPEP (*Système Apprenant Rapide pour les Programmes de Premiers Épisodes Psychotiques)* [48], the first RLHS for EIS in Canada, following substantial investment in EIS by the Quebec Ministry of Health and Social Services. The 18 existing EIS programs in 2016 expanded to a network of 33 EIS teams dispersed throughout Quebec by 2020 [48, 49]. Our multi-stakeholder team implemented SARPEP in 11 of the Quebec EIS, where more than 128 healthcare professionals, including 33 psychiatrists, 11 team leaders, and 10 managers, were providing services to more than 1695 active patients, with 734 new cases annually. These very diverse EIS in terms of the socio-geographic characteristics of the catchment areas (e.g. urban versus semi-rural), years of operation (e.g. < 5 years versus > 10 years) and patient age ranges covered were selected to represent the Quebec reality. Stakeholders (former service users, family members, psychiatrists, managers, team leaders) and researchers participated in all phases of the SARPEP project, starting with the selection of meaningful EIS quality indicators. As described in Table 2 of our protocol paper [48, p. 6], all stakeholder groups were involved in the various steps for co-creating SARPEP: identification of relevant indicators, selection and co-creation of digital tools (e.g. REDCap data collection platform) and conception and participation in capacity-building activities (e.g. conferences, webinars, co-creation of clinical tools, paired program mentorship).

The primary objective of the SARPEP evaluation project was to determine the feasibility and acceptability of implementing a RLHS in EIS [48], using the five dimensions of the RE-AIM framework [50] (Reach, Effectiveness, Adoption, Implementation and Maintenance) to achieve this aim. Using the RE-AIM framework allowed us to meticulously evaluate RLHS processes and outcomes (e.g. acceptability, fidelity, sustainability) to ensure not only that measures were adopted, but also to capture the processes that were effective in promoting the uptake and sustainability of practices over time in the RLHS [51]. The present study reports the qualitative findings from focus groups conducted with SARPEP stakeholders, adding depth and insight to the quantitative results [79] and enhancing rigour by integrating multiple perspectives including those of service users and families.

Methods

Context

A digital infrastructure with a user-friendly interface was designed and implemented, including three technologies for routine data collection, aggregation and sharing (every 3–4 months) among EIS. Data were collected from: (1) team leaders on their program practices (REDCap platform); (2) service users and family members, using: (a) "Happy or Not" digital terminals located in waiting rooms (see Fig. 1) and a mobile app to collect data from a three-question evaluation of services received that day, and (b) an in-depth electronic questionnaire on care received and nine recovery dimensions including health and quality of life (REDCap platform).

The collected data were aggregated and anonymized. Data analysis and graphical data visualization performed by the digital infrastructure provided participating programs with real-time feedback on how their practices reached standards, compared with other

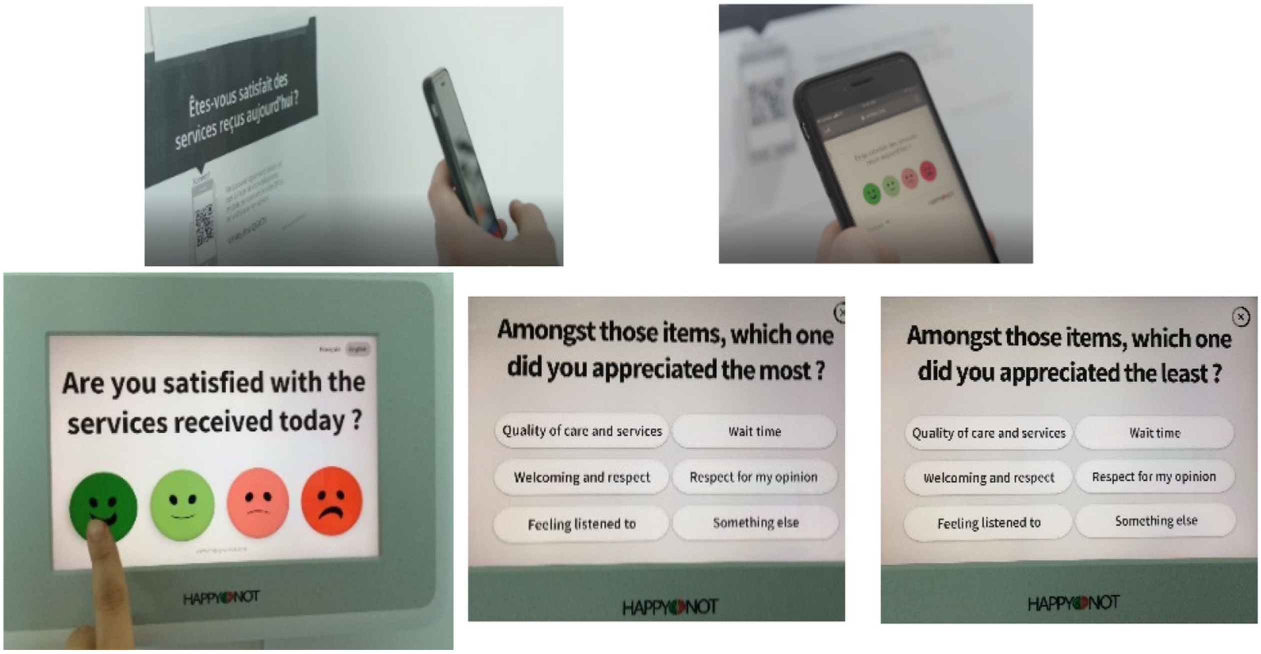


Fig. 1 The "Happy or Not" terminal for service user evaluation

Table 1 Focus group recruitment and composition

	Service users[a]	Family members[b]	Psychiatrists[c]	Managers[d]	Team leaders[d]
Contacted	9	4	9	8	10
Responded positively	6 (67%)	3 (75%)	4 (44%)	7 (88%)	8 (80%)
Participated[e]	5 (56%)	2 (50%)	4 (44%)	6 (75%)	7 (70%)

[a] Of the nine service users invited, six were former service users involved in the design and integration of SARPEP (of which many were, or had been, peer workers in EIS; one who was not a peer worker but a very recent EIS user, discharged from EIS), and three were current EIS service users who used the SARPEP digital platform, but were not involved in the design of SARPEP. Service users were divided into two focus groups (one with three participants, the other with two), because their availabilities did not match, precluding formation of a single group

[b] The four family members invited were actively involved in SARPEP design and integration

[c] The head psychiatrists of only nine EIS were invited, to avoid bias and because those from the two other EIS were also principal researchers in SARPEP (A.A.B., M.A.R.)

[d] Some teams did not have team leaders or managers at the time of the focus groups because of staff turnover

[e] The discrepancy between positive responses and participation occurred because some participants (most of whom had already signed consent) did not show up for the focus group

SARPEP programs, and tailored recommendations for reaching the targeted best practices. However, family members and service users did not receive graphical feedback on their data during the study, as development of this component was still ongoing. SARPEP also offered community of practice activities, leveraging insights from data to build program capacity while aligning program practices with provincial standards.

Study design

Qualitative evaluation of the SARPEP project followed publication of the study protocol [48]. All stakeholders were invited to participate in focus groups: service users, family members, psychiatrists (medical directors of their respective EIS), managers (decision-makers overseeing mental health services in public health organizations located in catchment areas where EIS operated) and team leaders (team coordinators of clinical activities and staff, who also worked as case managers). Focus group methods were selected, as small group discussions generate rich data from individuals with a shared interest, who may support or disagree on issues [52]. To avoid power imbalances, homogeneous stakeholder groups were created (e.g. service users only, team leaders only), creating safe spaces where participants could speak freely.

The qualitative research incorporated the RE-AIM framework [50], while development of the focus group questions drew upon the five dimensions of the Lessard et al. [53] LHS, namely: goals pursued by a RLHS in promoting evidence-based, quality care; a social dimension focused on creating community; a technical dimension concerning integration of digital data into routine care; a scientific dimension enabling learning, innovation and discovery; and an ethical dimension to ensure that learning and innovation activities in the RLHS protected patient rights and privacy.

The five RE-AIM dimensions [50] used to guide data collection were:

- Reach: Representativeness of the focus group participants, shown by the number of participants from each stakeholder group (service users, family members, psychiatrists, managers, team leaders) [54], reflecting stakeholder involvement in SARPEP.
- Effectiveness: perceptions of RLHS capacity to promote evidence-based, quality care in EIS.
- Adoption: perceptions regarding the feasibility for EIS to integrate data collected on indicators and digital technology into routine care, including the relative importance of indicators, their meanings and the ease/difficulty of collecting data on them.
- Implementation: Perceptions on the deployment and uptake of three innovative digital technologies for collecting and aggregating data and sharing feedback on data analyzed in routine care (e.g. service user's recovery self-assessment and clinical service evaluations), as well as on measures to protect patient rights and privacy.
- Maintenance: Perceptions of how the RLHS maintains and fosters a learning community, innovation and discovery.

Recruitment and participants

Eleven of the total 33 Quebec EIS were purposefully selected for the SARPEP pilot project using maximum variation sampling on the basis of a number of distinguishing characteristics: environment (academic/non-academic affiliation), socio-geographic area (urban, semi-urban, rural) and presence of a higher concentration of vulnerable populations (e.g. First Nations, immigrant, racialized youth) in the applicable catchment area, years of operation (<5 years versus >10 years) and

Table 2 SARPEP indicators presented during focus groups

INDICATORS	Examples
1. Service users' engagement and satisfaction with services	• Services adapted to the needs of service users • Youth-friendly environment • Disengagement • Outreach practices • Youth satisfaction
2. Family engagement	• Type of intervention offered • Percentage of families reached • Number of visits • Family member satisfaction
3. Access to care – Pathways	• Direct access • Referral sources, including self-referral and community referral • Inclusion and exclusion criteria • Number of contacts before access
4. Access to care – Systemic delays	Time between referral and: • First contact • First assessment • Start of treatment
5. Continuous education	• Number and type of continuing education events attended by workers • Supervision and mentoring
6. Provider-to-patient ratios	• Patient: mental health professional ratio • Patient: Psychiatrist ratio
7. Evidence-based and recovery-oriented practices	• Cognitive behavioural therapy, family intervention, employment or study programs, integrated treatment for substance use disorders and peer support • Types of specialists who offer interventions • Percentage of patients receiving long-acting injectable antipsychotics • Percentage of patients receiving clozapine
8. Self-reported recovery outcomes by patients	• Patient evaluations of their health, recovery and quality of life

age-related admission criteria for service users (adolescents only, young adults only, both). EIS were also selected for their diversity in terms of previous implementation challenges and interest in improving services.

The research coordinator sent emails inviting to the focus groups all stakeholders still actively involved in designing and implementing SARPEP (except researchers) (Table 1). Therefore, all those involved as head psychiatrists, team leaders and managers from each of the 11 programs were invited. All family members and service users involved in the design and implementation of SARPEP were also invited, as well as some active service users who used the electronic data capturing platform. The focus group moderator contacted interested stakeholders to explain the study and complete the consent process. With the aim of fostering a secure space for open discussion, and keeping in mind issues such as power imbalance, six focus groups (1.5 hrs. each) were conducted: two with service users, and one each with family members, psychiatrists, managers and team leaders.

Materials and data collection

Regarding questionnaire development, the general topics used in the focus groups were agreed upon by all stakeholders, while the specific questions were developed by the research team in line with the RE-AIM framework. The open-group discussion of the focus group format maximized information-sharing on individual experiences, perceptions and the impact of SARPEP on stakeholders' work and the EIS, including willingness to change, attitudes toward data collection (SARPEP indicator, Table 2) and facilitators/barriers to RLHS implementation.

The focus groups were conducted online (Zoom platform) and co-facilitated by a trained moderator (M.S.S.) and senior research staff (K.M.), both experienced with EIS and focus groups but not otherwise involved in SARPEP. Engaging facilitators without direct involvement in the SARPEP community aimed to enhance sharing and minimize desirability bias among participants. The sessions were conducted in French and audio-/video-recorded; the audio files were transcribed verbatim.

Data analysis

The overall analytical deductive approach was theory driven, using the five dimensions of the Lessard LHS to develop focus group questions and the RE-AIM framework for analysis. Following the qualitative research process from Braun and Clark [55], team members first read the full transcripts, checking them for accuracy.

Researchers (M.F., M.S.S.) developed a standardized code book sensitive to the RE-AIM framework [50] and Lessard [53] LHS dimensions. Data coded independently by the researchers were verified by the project coordinator, then mapped onto tables for the five respondent groups, whose experiences were then compared/contrasted. Analyses and feedback involving multiple team members ensured methodological effectiveness [56] and enhanced rigour. The analyses, produced in French, included identification of themes and sub-themes, adding descriptions/links between them. At the writing stage, the quotations were translated into English (J.S.), with oversight by K.M. and A.A.B., who are fluent in both languages. The principal investigators (A.A.B., M.F., S.I., M.A.R.) reviewed and refined the themes and sub-themes after exposure to the various analytical phases, including meetings to discuss previously shared analyses. The analysis was further deepened as research team members elaborated drafts of the manuscript.

Study participants provided member checking of the manuscript, further enhancing trustworthiness of the data. Senior researchers experienced in qualitative methodology and implementation science trained and mentored research staff throughout the research process. The study findings presented below follow the consolidated criteria for reporting qualitative research (COREQ) [57], a 32-item checklist and recommended tool by the Enhancing the QUAlity and Transparency Of health Research (EQUATOR) database [58].

Positionality

As researchers, we continuously reflect on our roles, status and power dynamics within our interactions with stakeholders, for example, members of participating EIS in SARPEP, service users and family members. Uniquely, A.A., M.F., S.I. and M.A.R. advocate for, and greatly value, participatory methods where stakeholders, particularly service users and family members, participate as co-creators in our team research projects. We applied these principles to SARPEP, where EIS team leaders, staff and managers, as well as service users and family members, were treated as co-researchers/co-creators of the project and evaluation phases (qualitative and quantitative). This participatory approach acknowledges the unique positionalities of all contributors, ensuring that their knowledge and experiences are valued in the co-creation of health solutions. Positionality is a core dimension of rigour that aligns with the core tenets of the SARPEP project: adaptability, inclusivity and responsiveness in real-world contexts. This is also the primary criterion for assessing the rigour and trustworthiness (credibility, authenticity and integrity) of the qualitative research process.

Findings

This section presents the findings according to the RE-AIM framework:

Reach

The six focus groups included each stakeholder group (see Table 1 for details) and represented a majority of those invited, for most groups. The focus group participants generally represented the diversity of the SARPEP stakeholders in terms of individual characteristics, experience in EIS and professional background. For example, the focus groups with service users, managers and psychiatrists represented different sexes and gender identities; the team leaders included diverse professional backgrounds (social worker, occupational therapist, nurse and psychologist); and among the psychiatrists, two had been working in EIS for less than 5 years, one for more than 5 years and one more than 10 years.

Effectiveness

Before implementation of SARPEP, few EIS routinely collected clinical or program-level data, and only rarely asked service users or family members to complete forms or questionnaires. Moreover, data were not systematically analyzed, unless for research purposes, yearly program evaluations or reports:

> *We work with an Excel database that we created ourselves. For sure, (data) were missing compared with what you would find in SARPEP. It's not the same thing; some information requested by SARPEP was unavailable to us, which forced our team leader to rework things to find certain data (Psychiatrist 3).*

SARPEP offered EIS an opportunity to improve their measurement-based practices. Importantly, the feedback provided by SARPEP comparing EIS performance on various indicators offered a comparative perspective on their services, allowing EIS to better evaluate their strengths and weaknesses, adherence to norms, and areas for improvement:

> *In terms of the project, I would say that it provides a view of the services we offer compared with what is offered in other EIS: what our strengths are; what points we need to improve as a clinic (Psychiatrist 4).*

Psychiatrists and team leaders underlined the timeliness of the SARPEP project, coming in the early days of the pandemic, with more communication difficulties and a loss of resources, as one team leader described:

> *I find that (SARPEP) has helped us keep a common thread in sustaining an EIS. Because, with all that*

> *has happened … the pandemic, and all that, I would say that we lost some benchmarks along the way. The SARPEP project, coming at the time it did, allowed us to keep track of what we were doing, to understand what an EIS is, and how to provide the service for the public and for our young people (Team leader 7).*

One psychiatrist emphasized that the new RLHS put Quebec EIS "on the map as a community that offers early intervention services for youth with psychosis …" (Psychiatrist 1). For another psychiatrist, the RLHS helped them evaluate data collected (or not) in their program and identify areas of improvement. Participating in a RLHS also encouraged more disciplined data collection, considered a positive outcome as it prompted self-assessment in their program (Psychiatrist 4).

Regular and automatic feedback provided to the EIS after each period of data collection (see Fig. 4) was well received and valued, as a team leader described:

> *[As a new EIS], we are finishing our first 3 years [of operation]; so, I am thinking about transition [to other services post-EIS]. For me, it was very helpful to know how this was done elsewhere, and how we could apply this to our clinic. I find that it's helpful for newer EIS to sit down with more established ones, and learn [from them] how to do things, share tools, and how to use them … it's really great (Team leader 2).*

Overall, participants across stakeholder groups emphasized that SARPEP had created a "common thread" or "sharing forum" for mutual assistance among EIS, keeping them vigilant about performance and opportunities to improve their services:

> *It offers a sharing forum between EIS (Family member 1).*

Adoption:

Feasibility of integrating indicators, or digital data, into routine care

Focus group participants were given a list of eight indicators (Table 2) identified from a synthesis of the literature and EIS guidelines [48]. SARPEP stakeholders had selected these indicators by consensus as impactful for service user outcomes and service quality but amenable to change within the initial, two-year implementation period.

Participants were asked to comment on the indicators in terms of personal recovery for service users and quality of care for them and family members, and the ease or difficulty of collecting these data. Participants regarded the indicators as precise, relevant and helpful:

> *I think the indicators are pretty specific. They give you a general idea of how things are going (Service user 1).*

Opinions also converged around the importance of certain indicators. Several participants viewed access to care as most urgent and highly consequential for the quality of care and service user recovery:

> *I would say that the wait time for access to care is important, so the person's condition doesn't deteriorate rapidly (Service user 5).*

Stakeholders endorsed the establishment of standardized practices throughout Quebec EIS to support RLHS implementation, for instance, developing standards around referral sources, inclusion/exclusion criteria for access to care and direct access:

> *… there are several important aspects to consider in the process of accessing care. In terms of inclusion and exclusion criteria, to have a good understanding of who needs to enter EIS, or not; as well as referral sources and direct access, because I think that these measures are still not well established in a homogeneous manner everywhere in Quebec (Manager 4).*

Participants viewed reinforcing staff capacity and competence as essential in actualizing the RLHS. Managers prioritized the need for proper service intensity, some emphasizing the need for continuous staff training and mentorship in a fluid environment:

> *Continuous staff training is also a <u>must</u> (Team leader 2).*

Appropriate service user/provider ratios also helped maintain service delivery standards:

> *For sure, in the larger scale of things the patient/clinician ratio is important for good services … (Service user 2).*

All stakeholder groups viewed the indicators aligned with service user and family satisfaction and engagement as crucial elements for EIS, reflecting acceptability of the RLHS by the primary beneficiaries:

> *Engagement and satisfaction of youth … I would say that it's the patient who is at the centre of everything (Family member 2).*

Concerning the ease or difficulty of collecting data on indicators, quantifiable indicators were generally considered easiest, as noted below:

> *… delay in access to care is easy. It's quantitative, so it goes well enough (Manager 1).*
> *It's about dates in a system (Service user 1).*
> *… the patient-provider ratio, that's easy to count (Service user 2).*

One team leader found family engagement more difficult to measure than other indicators such as staff training activities:

> *It was easier to keep statistics on group interventions, presentations and conferences than on family engagement (Team leader 5).*

Asked to comment on the quality of services, participants offered different insights. They viewed data collection following clinical appointments using the "Happy or Not" devices and the REDCap questionnaire (via QR code) as straightforward for service users (Service user 5; Psychiatrist 3). For instance, service users responding to the question: "Are you satisfied with the service you received today?" would select the appropriate smiley-face emoticon button on the terminal: very happy, happy, unhappy or very unhappy (see quotes: next section). However, some clinicians mentioned difficulties around inviting patients to complete the REDCap questionnaires:

> *For us that was a clear challenge, the whole question of having patients fill out (satisfaction) questionnaires (Psychiatrist 3).*

Stakeholders viewed data collection as challenging, due more to subject matter than technical aspects. Service user satisfaction was one area:

> *Satisfaction is also difficult to grasp, I find, because we are often in relationships where patients are under involuntary care, or some kind of treatment order … (Manager 3).*

Service users noted another challenge in collecting information about engagement in treatment related to the issue of disengagement:

> *Information about engagement in treatment can be difficult to collect when the person disengages from treatment. It often becomes difficult to know why, exactly the situation … it can be difficult to obtain information directly from the person who left … (Service user 4).*

Service users also found it potentially difficult to capture data on family engagement, as family members bring different standpoints:

> *A family has several members. Should families respond as a unit? That would be biased. Should each family member fill out their own questionnaire, one day the brother and another day the sister? Like, if one day it's the brother or the sister who sees the patient, or not (Service user 2)?*

Providers endorsed data collection around recovery-oriented practices and patient-reported outcomes, but did not always know whether these data were being collected:

> *I was not aware of patient self-assessment of clinical outcomes, and I'm very, very interested in this. A clinical measure for symptoms, but also for recovery (Manager 1).*

Various stakeholders also reported needing further data (Table 3).

Psychiatrists expressed the need for specific indicators to better track symptomatic and functional patient outcomes over time:

> *We are talking about an illness that affects functioning, but we do not have the elements that indicate improvement or stagnation in the patient's level of functioning (Psychiatrist 1).*

Figures 2 and 3 show how different stakeholder groups positioned themselves in relation to the relevance and simplicity of collecting data on indicators used in the SARPEP project. Overall, the data suggest that participants agreed on the meaningfulness of the selected indicators (Fig. 2), yet some disagreement emerged on the ease (+) or difficulty (−) of collecting the relevant data (Fig. 3).

In this figure, (+) means indicators are considered easy to collect, and (−) not as easy to collect. The experience of participants in using different technologies to collect data are part of both the Adoption and Implementation dimensions of the RE-AIM framework, as described in the following section.

Implementation and Maintenance: the feasibility of implementing the RLHS in EIS

Deploying and using technologies

Stakeholders viewed the REDCap digital platform as an effective tool, but found data reporting time consuming. Yet having an infrastructure to support data collection, visualization (Fig. 4) and sharing was appreciated:

> *I think it is pertinent to continue filling that out … However, this is not a small task. It's time-consuming (Psychiatrist 2).*

Team leaders found the periodic evaluation of their work through graphical feedback especially useful, and important for lifting morale. The reports gave clear

Table 3 Results. Additional data related to adoption, implementation and maintenance

Themes	Quotes	
Adoption		
Feasibility of integrating indicators, or digital data, into routine care	I also … think they are all important … (Manager 1). … I think that all these indicators are important. But I also believe it would be important to know to what extent the programs are capable of collecting this information in a reliable way (Psychiatrist 1).	*Moi aussi trouve que y sont tous importants* (Gestionnaire 1). *… Ben je pense que tous ces, tous ces items-là sont importants. Mais encore est-il je crois que c'est important de savoir dans quelle mesure les programmes sont capables de collecter cette information de manière … de manière fiable* (Psychiatre 1).
Indicators – Access to care	For our young people, I find [important], to take them in at the very beginning … (Team leader 2). In the first place, I would say the access to care process and the time it takes to access care are important… (Manager 5). I really agree, we see that delayed access makes a difference in the speed of recovery; … there is also a difference in the interventions that are needed when we delay access compared to when we move very quickly. I also find that the process of accessing care is very important … that we ensure fluid and rapid communication and have the information needed to serve the young person – very, very important (Team leader 4). I find that … the delay in accessing care is super important when we talk about the quality of services (Team leader 6).	*Pour nos jeunes, j'trouve, d'les prendre au début, début* (Chef d'équipe 2). *Le processus d'accès aux soins, puis le délai d'accès aux soins dans un premier temps qui sont importants …* (Gestionnaire 5). *Et j'suis vraiment d'accord, le délai d'accès on voit vraiment la différence dans la rapidité du rétablissement, puis les interventions nécessaires si jamais on tarde versus si on va très rapidement … Le processus d'accès aux soins, j'trouve que c'est aussi très important. De s'assurer d'une communication fluide, rapide, d'avoir l'info qui faut pour servir le jeune, très, très important* (Chef d'équipe 4). *… moi j'trouve que … le délai d'accès aux soins est super important quand on parle de qualité de service* (Chef d'équipe 6).
Indicators – Staff capacity and competence	… the other thing for me is continuous staff training. We know that there is enormous turnover in our teams, as all throughout the healthcare system; so, it isn't easy (Manager 4). I see that with the new workers who arrive at the clinic, their need for supervision, for mentoring in terms of this approach. So, I also find this important (Team leader 5).	*L'autre chose pour moi c'est la formation continue du personnel. On sait qu'on a énormément de roulement dans nos équipes pour, ben comme dans l'ensemble du système de santé, puis c'est pas facile* (Gestionnaire 4). *… moi j'vois avec des nouveaux intervenants qui sont arrivés à la clinique tout le besoin de supervision, de mentorat par rapport à cette approche-là aussi. Donc ça aussi j'trouve ça important* (Chef d'équipe 5).
Important indicators – Satisfaction and engagement	The satisfaction of young people and their families is, in my view, critical among the indicators that were chosen (Manager 2). For me, the priority indicators are the delay in access to care, and engagement with the family. This is important because the providers can be working in one direction, while the family has diverging opinions; so, it is better that everyone works in the same direction (Service user 3). … to adapt to the young people, to reach them more easily, in a way that best accommodates them (Team leader 5).	*Les éléments de satisfaction des jeunes et d'leur famille sont, à mon avis, critiques dans les indicateurs qui ont été choisis* (Gestionnaire 2). *Ben moi c'est ça, mes indicateurs en priorité c'est délais d'accès aux soins, l'engagement avec la famille et l'entourage, pour moi, c'est important parce que les intervenants peuvent travailler dans une direction et la famille peut avoir des opinions divergentes donc on est mieux de travailler tout le monde dans la même direction* (Utilisateur de service 3). *… s'adapter aux jeunes, les atteindre plus facilement, de la manière qui leur convient le mieux* (Chef d'équipe 5).
Indicator – Dis/satisfaction	… but I think that recovery is a notion that is very personal … Someone may think that a person has recovered well, whereas for someone else … the person has not recovered that much (Service user 2).	*Je pense que le rétablissement, c'est difficile de dire que … c'est une notion qui est très personnelle, le rétablissement. Pour quelqu'un, la personne va être bien rétablie et pour un autre, la personne ne sera pas tant que ça* (Utilisateur de service 2).

Table 3 (continued)

Themes	Quotes	
Indicator – Need for new data	We do a systematic follow-up of the clients … Client evolution is evaluated rigorously. I'm going to know if there was any family intervention, but I won't necessarily have the number of family interventions (Team leader 7). … they talk about the patient's self-rated clinical outcomes, but how about the data on vocational status, financial autonomy, those things … (Team leader 1). Motivation to pursue a career, to have a stable job, university studies (Service user 1). Maybe their extra-EIS activities, those that don't take place at the EIS (Service user 1). Substance use, because more than half of the youth who arrive here use substances (Team leader 1).	*L'évolution de la clientèle, ça on le fait de façon rigoureuse. Puis c'est un peu là-dedans où est-ce que j'vais savoir si justement y a eu de l'intervention familiale ou non, mais j'aurai pas le nombre nécessairement d'interventions familiales* (Chef d'équipe 7). *… y disent l'évolution clinique auto-rapportée par le patient, mais les données sur le statut vocationnel, l'autonomie financière, ces choses-là* (Chef d'équipe 1). *La motivation de poursuivre une carrière, donc avoir un emploi stable, quelque chose à l'université* (Utilisateur de service 1). *Peut-être les activités extra PEP, donc pas dans le PEP* (Utilisateur de service 1). *La consommation parce qu'y a plus que la moitié de nos jeunes qui arrivent qui consomment* (Chef d'équipe 1).
Indicators – Symptomatic and functional outcomes	In this list, there are no indicators of symptom severity and evolution. We are talking about an illness that affects functioning, but we do not have the elements that indicate improvement or stagnation in the patient's level of functioning (Psychiatrist 1). One important element is the treatment algorithms. How can they be implemented in an easy, practical, pragmatic way, and how can they be followed over time (Psychiatrist 1)? It would be very, very important, I think, to evaluate program performance (Psychiatrist 2).	*On parle d'une maladie qui affecte le fonctionnement. On n'a pas d'éléments non plus qui reflètent un peu l'amélioration ou bien la stagnation de patient sur le plan du fonctionnement* (Psychiatre 1). *Donc y a un élément important, c'est les algorithmes de traitement. Comment est-ce qu'on peut le mettre en place de manière facile, pratique, pragmatique et comment est-ce qu'on peut le suivre au cours du temps* (Psychiatre 1)? *Puis ça serait très, très important, je pense, pour voir … pour, c'est ça, évaluer la performance d'un programme* (Psychaitre 2).
Implementation and Maintenance Deploying and using technologies	I'm going to be honest: given the time at my disposal, I wasn't able to play around with this questionnaire … But, let's look at it in a positive way; the reality is that what it takes to implement this is manpower (Team leader 4).	*J'vais être honnête, ce questionnaire-là avec le temps que j'avais, j'étais pas capable d'aller jouer dans ça … Mais la réalité c'est que si on regarde de façon positive quoi faire pour implanter ça, ça nous prend … ça prend, ça prend la main-d'œuvre* (Chef d'équipe 4).
Graphical feedback	This [data and graphical feedback] brings concreteness in our everyday actions (Team leader 7). It's also fun for them to see what went well in the previous 3–4 months, what we still need to work on, or to improve … it also allowed us to identify objectives … case managers also expressed satisfaction with this (Team leader 5). … when we see that it was a good month, that we had some positive comments (from the [visual feedback]), we transmit that to the team; it's fun for providers to know that they are appreciated by the clients and this helps morale among the troops (Team leader 1). I liked that this brought us in contact with the provincial government EIS counsellor, that it was documenting for our leaders and managers some of our needs based on the data we collected (Team leader 2).	*Ça ramène de la concrétude dans nos actions de tous les jours. Ça, c'est clair* (Chef d'équipe 7). *C'est le fun aussi pour eux aussi de voir qu'est-ce qui, qu'est-ce qui a bien été dans les 3–4 derniers mois, c'qui nous restait à travailler ou à améliorer aussi. Fait que ça permettait aussi d'identifier des objectifs … Les intervenants ont signifié aussi leur satisfaction par rapport à ça* (Chef d'équipe 5). *… quand mettons dans le mois on voit qu'on, que c'était un bon mois, puis on a ben eu des commentaires positifs, ben on le transmet à l'équipe, puis c'est comme le fun pour les intervenants de savoir que y sont appréciés par la clientèle, au niveau du moral des troupes* (Chef d'équipe 1). *J'aimais le fait que ça nous ramène quand même à être en contact soit avec notre conseiller au ministère … de documenter auprès de nos chefs, auprès des administrateurs certains besoins qu'on a de façon un p'tit peu plus … c'est comme, on a documenté en tout cas à partir de données qu'on a colligées* (Chef d'équipe 2).

Table 3 (continued)

Themes	Quotes	
Satisfaction questionnaires	You end your meeting, it goes well; then you give [the evaluation form] to the patient. But it's a bit embarrassing; it's like asking to give me positive feedback (Psychiatrist 4).	*Fait que là tu finis ta rencontre, ça se passe bien, tu lui donnes, mais c'est un peu gênant. Ça va me faire des commentaires positifs* (Psychiatre 4).
Data collection on service user and family satisfaction	There were some weeks where all the providers talked about it with all the patients at each meeting. We had one or two evaluations. Then, we tried to go in a strategic fashion, because sometimes … it's the first meeting with patients; they can still be perplexed, symptomatic. So, we were trying to 'time' the moment that we talked about it. I'm not sure if this is a mistake, or if it's really something we could work on (Psychiatrist 2).	*Y a eu des semaines où tous les intervenants en ont parlé avec tous les patients à chaque rencontre. On a eu une ou deux évaluations. Ensuite on a essayé d'y aller de façon stratégique parce qu'effectivement des fois on … c'est première rencontre avec des patients, puis y peuvent être encore perplexe, symptomatiques. Donc là on essayait de timer le moment où on en parlait. On sait pas trop si c'est une erreur ou si c'est vraiment quelque chose sur lequel on pourrait travailler* (Psychiatre 2).
Measure for client satisfaction using "Happy or Not" and REDCap satisfaction survey	The "Happy or Not" for me is playful, and it's right at the door. So, it's fun, 'flashy' (Manager 3). I see that this gives me a very quick idea immediately after an appointment whether people are satisfied (Manager 1).	*Le « Happy or Not» pour moi est ludique, puis y est vraiment à la porte de sortie. Fait que y est le fun, y flash* (Gestionnaire 3). *Moi j'vois d'avoir une idée très rapide après un rendez-vous si les gens sont satisfaits dans l'immédiat* (Gestionnaire 1).
"Happy or Not" and location in the clinic	We installed the famous machine … we couldn't put it just anywhere because there are also places in the hospital that are multifunctional … maybe it isn't installed in a good place (Psychiatrist 2). We don't have offices or waiting rooms. So, it's complicated to move the big tablet around. We don't have a fixed place to put it (Team leader 2). … well, I'm speaking for our place. I don't know about elsewhere, but it is in the waiting room. Not very popular with the infection control department (Manager 3).	*Nous on l'a installé, la fameuse machine … on pouvait pas la mettre n'importe où parce que nous aussi y a des lieux dans l'hôpital qui sont multifonction … Fait que on cette machine-là installée, mais peut-être qu'elle est pas installée au bon endroit* (Psychiatre 2). *Qu'on n'a pas de, nécessairement de locaux ou de salle d'attente. On est assez nomade. Fait que ça, c'est compliqué de trainer la grosse tablette, on n'a pas d'endroit fixe où la mettre* (Chef d'équipe 2). *J'parle pour chez nous, je sais pas ailleurs, mais y est dans la salle d'attente. Y est pas beaucoup aimé de la prévention des infections* (Gestionnaire 3).

Table 3 (continued)

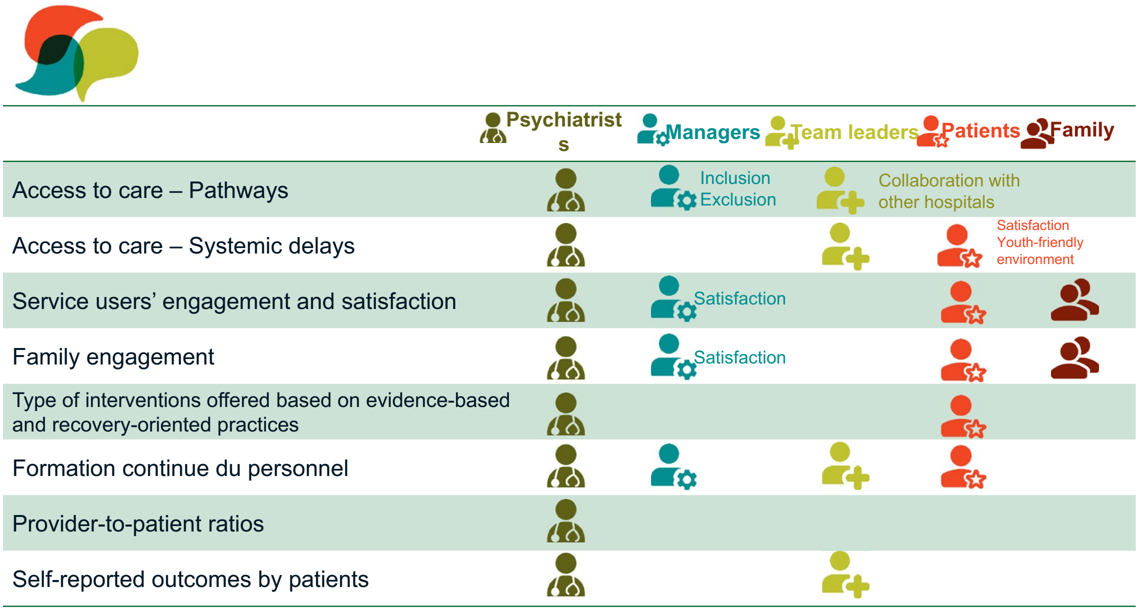
Themes	Quotes	
RLHS protects the rights and privacy of service users and maintains equity	… we have to pay a lot of attention, introducing things slowly, slowly … step by step, and see what the problems are, what difficulties we encounter in using these tools. We also need to consult with IT services, with the ethics committee, with patients. Everyone needs to be comfortable with this, and we must do it in stages and make sure that we don't begin with a big project and then it flops and doesn't work. A few clinicians who are engaged in this type of activities need to be included, a few patients, and then improve the quality of the experience as we increase our experience … We have been saying this for 20 years, but I hope we will get there. These types of platforms will probably be part of our everyday life in future (Psychiatrist 1). I think that, yes, it's how these data are utilized, where they are stored. This is confidential information, that's it (Service user 3). But I'm thinking now, she (daughter) thinks that her cell phone is being hacked, you know, so if she goes to the doctor tomorrow morning, the last thing she wants is to respond on the tablet … (Family member 1). I am trying to think of someone young, like me, who is in the streets; well, I don't think they will use it. They have other things to do than to spend 10 minutes filling out a survey in the clinic (Service user 3).	*… y va falloir faire très attention c'est-à-dire en introduisant les choses tranquillement, doucement, pas à pas et voir un peu quels sont les problèmes, les difficultés qu'on rencontre dans l'application de ces outils-là. Donc y faut également consulter avec nos services informatiques. Y faut consulter avec le comité d'éthique. Y faut consulter avec les patients. Y faut que tout le monde soit à l'aise avec ça et puis y faut que faire ça par étape et s'assurer que … s'assurer de ne pas commencer avec un grand projet et puis par la suite ça flop et ça ne fonctionne pas. Y faut inclure quelques cliniciens qui sont engagés dans ce genre d'activités, quelques patients et puis par la suite améliorer l'expérience et augmenter notre expérience …. Cela on le dit depuis maintenant 20 ans, mais j'espère qu'on va y arriver et ce genre de plateformes vont faire probablement partie de notre quotidien dans l'avenir* (Psychiatre 1). *Je pense que oui, c'est comment ces données-là sont utilisées, où est-ce qu'elles sont stockées. C'est de l'information confidentielle, c'est ça* (Utilisateur de service 3). *Mais je suis en train de penser en ce moment, elle pense que son téléphone cellulaire est hacké, la, tu sais … fait que la si elle s'en va au médecin demain matin, répondre sur la tablette c'est la dernière affaire qu'elle veut* (Membre de la famille 1). *J'imagine que mettons, j'essaie de penser à quelqu'un de jeune comme moi, mais qui est dans la rue, bien je ne pense pas qu'ils vont le prendre, il y a d'autres besoins que de prendre 10 minutes pour remplir le sondage dans la clinique* (Utilisateur de service 3).

Table 3 (continued)

Themes	Quotes	
RLHS maintains and promotes learning, innovation and discovery	… that helped the team somewhat to decide on what data to collect (Psychiatrist 1).	*Ça a aidé l'équipe de décider un peu sur quoi, qu'est-ce qu'on collecte un peu dans nos données* (Psychiatre 1).
	Sometimes I say to myself, 'heck, are we the only ones functioning like this?' … So, when we met, I said to myself, 'Okay, my reality isn't so different from that of other regions or teams.' So, when we met maybe twice in the past year … I found that it normalized our challenges as well as our successes, and the organization of our services. It was pleasant (Team leader 6).	*… des fois j'me disais coudonc on est-tu dans le champ, on est-tu tout seul à fonctionner comme. Fait que quand on se réunissait, j'me disais OK ma réalité est pas si différente des autres régions ou des autres équipes. Fait que moi j'ai apprécié quand on se réunissait peut-être … peut-être deux fois dans la dernière année. Mais ça normalisait, j'trouve, autant nos défis que nos bons coups, que l'organisation des services. C'était agréable* (Chef d'équipe 6).
	I think that we started there (capacity-building activities). This is the first time that, as a community of psychiatrists, of carers, we are together to discuss these problems. Before that, nothing existed (Psychiatrist 1).	*Je pense que là on commence. C'est la première fois que en tant que communauté de psychiatre, de soignants, de … on est ensemble pour discuter de ces problèmes-là. Avant ça n'existait pas* (Psychiatre 1).
	I don't think we have a sense of community for the managers … Or, maybe it's 'me', because I just arrived … (Manager 1).	*J'pense pas qu'on a un sentiment de communauté pour les gestionnaires … Ou c'est peut-être moi parce que j'viens d'arriver …* (Gestionnaire 1).
	It allows us to keep a common thread. It allows exchanges between coordinators, team leaders … It's like, yes, it keeps you aware of what's going on elsewhere, and then it feels good to get out of your little belly button (Team leader 7).	*Ç'a permis de garder un fil conducteur. Ça permettait des échanges justement entre les coordonnateurs, chefs d'équipe … c'est comme oui à l'affût de qu'est-ce qui se passe ailleurs, puis ça fait du bien de sortir de son petit nombril* (Chef d'équipe 7).
	I think this has surely had an impact, because it offers a sharing forum between clinics … From what I've seen, there was more openness, more ideas. There was more communication between the different EIS, and that in addition to the fact that the 2015–2020 mental health plan spoke specifically about family and close ones ("entourage"), so this increased engagement with families. I think that this also helped (Family member 2).	*Je pense que oui, moi. Ça a eu surement un impact parce que ça offre une tribune de partage entre les cliniques … qu'est-ce que j'ai vu, c'est qu' il y avait plus d'ouvertures d'idées, il y avait plus de communication entre les PEPP, et ça avec le fait que le plan santé mentale de 2015–2020 a parlé spécifiquement de l'entourage, qu'on devrait engager l'entourage, et qu'on devrait élargir nos affaires avec eux, je pense que ça a aidé aussi* (Membre de la famille 2).

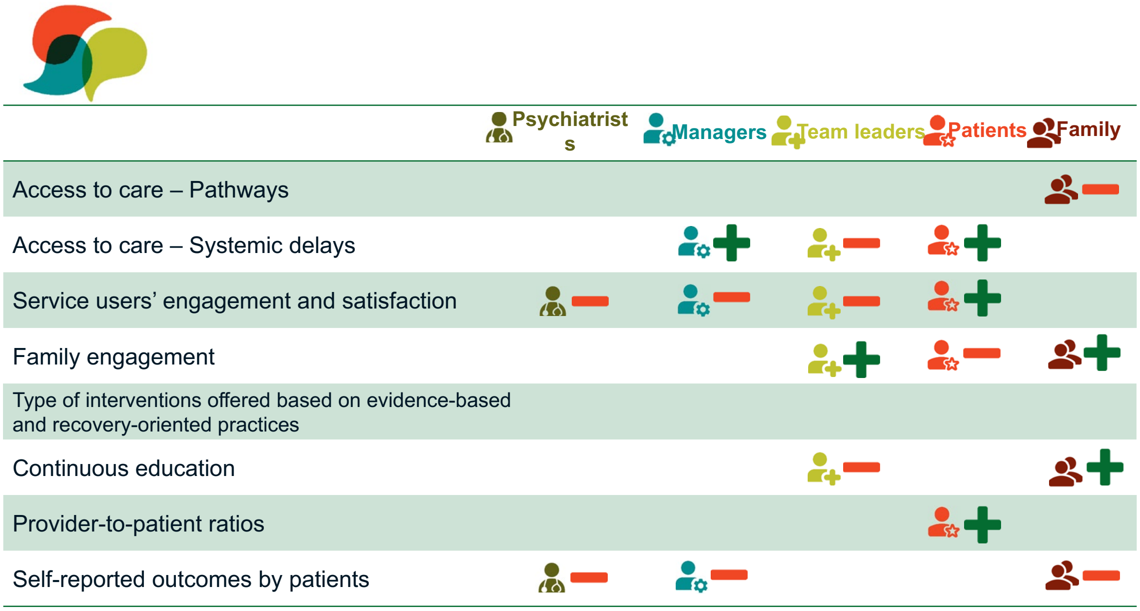
Table 3 (continued)

Themes	Quotes	
How SARPEP sustains and improves the RLHS over time	Basically, SARPEP should be better known to clinicians, managers, and higher-level managers, even the general directors of our health organizations. I think it has to be recognized … there has to be an awareness about SARPEP (Manager 3). I think that … what will really help, is when they rewrite the Quebec EIS guidelines. That will be super useful, and we have already been told about it … (Team leader 1). … there still remain challenges for our clinic. We don't fulfil all the requirements of the Quebec EIS guidelines. So, what we would like is that this … helps us perhaps to have a little more weight [credibility] with management to be able to continue to improve … (Manager 3). … it (SARPEP) allows the clinic to improve and put forward the concerns of young people, while adapting services to their needs and vision, to their image … To provide the best chances for success, recovery and to always aim for excellence in treatment … all this (Service user 3). We know that the data are going to be collated so changes can be made (Service user 2).	*À la base que ce soit mieux connu autant des intervenants, des gestionnaires, puis des gestionnaires de plus haut niveau voire même jusqu'aux directions générales. J'pense que faut que ça soit … faut que ce soit … pour être reconnu y faut que ce soit connu* (Gestionnaire 3). *Moi j'pense que tout ce projet-là, c'qui va vraiment aider, c'est quand y vont réécrire le cadre de référence des EIS au Québec. Ça va être hyper utile parce que nous on l'a dit* (Chef d'équipe 1). *… y reste encore des défis au sein de la clinique. On remplit pas toutes les exigences du cadre de référence. Donc ce qu'on aimerait c'est que ça, ça nous aide peut-être à avoir un peu plus de poids sur la gestion pour pouvoir continuer à améliorer* (Gestionnaire 3). *Ça permet toujours à la clinique de s'améliorer et de mettre de l'avant la préoccupation des jeunes … et de justement adapter leur service à leurs besoins, à leur image … Donner les meilleures chances de réussite, de rétablissement et de toujours viser l'excellence au niveau des soins, tout ça* (Utilisateur de service 3). *On le sait que les données vont être colligées pour qu'il y ait des changements* (Utilisateur de service 2).
How to improve SARPEP	… often the peer support worker could, from his experience, help people to open up more about their symptoms, to express themselves, which was good (Service user 3). In our program, we would like to include a patient partner, a peer support worker on the team … I think that could be very interesting for some clients who are a bit ambivalent about some of the proposed interventions (Manager 6). To have a family peer support worker in all the clinics! And to meet him/her at the beginning! Because I am working hard on that … (Family member 2).	*… souvent, le pair aidant pouvait de son expérience et ça aidait les gens à s'ouvrir davantage sur leurs symptômes et à oser s'exprimer, donc ça, c'est bien* (Utilisateur de service 3). *Du côté des Laurentides on aimerait bien pouvoir inclure un patient partenaire, un pair aidant dans l'équipe … J'pense que ça pourrait être intéressant pour certains clients qui peuvent être un peu ambivalents face à certaines propositions d'interventions* (Gestionnaire 6). *Avoir un pair-aidant famille dans toutes les cliniques! … Et le rencontrer au début! Parce que là je suis en train de travailler fort …* (Membre de la famille 2).



	Psychiatrists	Managers	Team leaders	Patients	Family
Access to care – Pathways	●	● Inclusion Exclusion	● Collaboration with other hospitals		
Access to care – Systemic delays	●		●	● Satisfaction Youth-friendly environment	
Service users' engagement and satisfaction	●	● Satisfaction		●	●
Family engagement	●	● Satisfaction		●	●
Type of interventions offered based on evidence-based and recovery-oriented practices	●			●	
Formation continue du personnel	●	●	●	●	
Provider-to-patient ratios	●				
Self-reported outcomes by patients	●		●		

Fig. 2 Stakeholders' acceptance of selected and used SARPEP indicators



	Psychiatrists	Managers	Team leaders	Patients	Family
Access to care – Pathways					−
Access to care – Systemic delays		+	−	+	
Service users' engagement and satisfaction	−	−	−	+	
Family engagement			+	−	+
Type of interventions offered based on evidence-based and recovery-oriented practices					
Continuous education			−		+
Provider-to-patient ratios				+	
Self-reported outcomes by patients	−	−			−

Fig. 3 Stakeholders' assessment regarding the ease of collecting data on selected and used SARPEP indicators

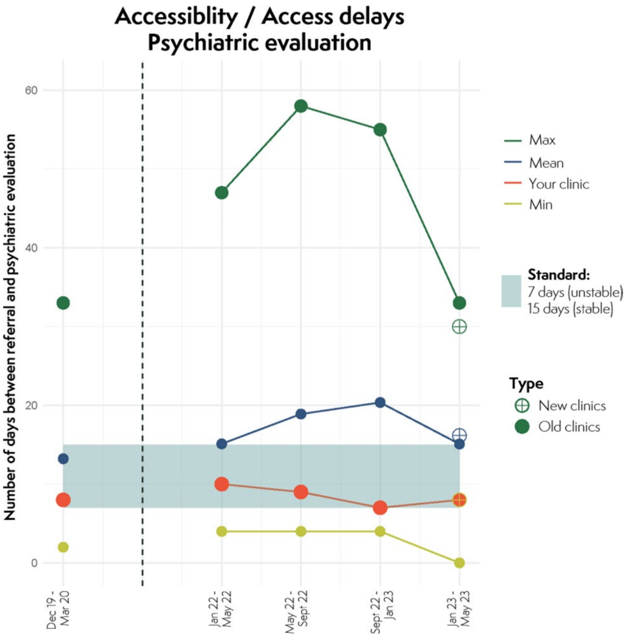


Fig. 4 Example of graphical feedback provided to the clinics after each round of data collection

indications of where the EIS stood in meeting their objectives and documenting needs:

> *I think if the parameters are very well and clearly defined, and very well collected, the information is reliable, and it will therefore always be useful to receive this information [graphical feedback] (Psychiatrist 1).*

This graphical feedback provides clinics with information on different indicators (such as access delays, by indicating the number of days between referral and the psychiatric evaluation) (Fig. 4). Clinics can track their own progress over time, and compare their performance to that of other programs, provincial averages and standards.

Many EIS managers and team leaders found it challenging to implement satisfaction questionnaires to service users and family members and observed that they were "not generating a lot of data" (e.g. Manager 3): "you could count on your fingers those who responded to the long-form questionnaire" (Team Leader 6). While clinicians and psychiatrists initially attempted to implement these questionnaires, many reported discomfort in asking patients to fill them out; uptake was therefore weak. Moreover, some noted concerns that the lack of systematic data collection risked biasing results in favour of individuals wholly satisfied or wholly dissatisfied, if not upset, after receiving services. Comments by stakeholders also reflected the challenge of replacing their informal client assessment practices with a more systematic evaluation process:

> *For sure, this is new to us, but we had difficulty getting clients to fill it out. There were reminders … but it wasn't filled out regularly by our clients. So, we still have things to work on regarding this aspect (Manager 5).*
> *You end your meeting, it goes well; then you give the evaluation to the patient. But it's a bit embarrassing; it's like asking to give me positive feedback (Psychiatrist 4).*

A service user participant also underlined the importance of encouraging service users to express their opinions about their care; otherwise "people will only write when they are frustrated, and that can bias the data collection" (Service user 3).

Other stakeholders considered data collection on service user and family satisfaction as extremely important, suggesting that the timing of questionnaire administration could impact client uptake and the relevance of their feedback. They also viewed the QR code as an effective solution for accessing questionnaires:

> *I find that there are pivotal moments in follow-up where, if we encouraged the young person in a well-defined way to fill it out, we would maybe get better feedback … (Team leader 6).*

On using the "Happy or Not" terminal to measure client satisfaction, participants generally gave positive feedback (Fig. 1):

> *I would say that it's set up well. It was just in the corridor where we go for our psycho-ed activities or meetings with providers. The tablets are big enough, so they're easy to read (Service user 4).*

Others described issues that made installation of the "Happy or Not" terminal somewhat complicated, including distancing measures during the pandemic, sharing space with other services or lack of a fixed clinic location since they were mainly offering outreach services.

Stakeholder perceptions of how the RLHS protects the rights and privacy of service users

Digital tools and the shift to measurement-based care were viewed by professionals as inevitable. The key issues around use of digital tools concerned the need to develop competence around technical issues, ethical issues and a desire to put people at ease:

> *Currently, there is a strong will at the ministerial level; there is a culture of measurement that comes with a new technology every six months or so … and*

> *documents to complete. Then, we mentioned earlier how important it was to convince our supervisors of various elements (Manager 2).*

For some service users and family members, confidentiality and data security were important issues:

> *This is not a worry, but rather a comment. I would say [what is important is] that the psychological profile stays confidential. This is the only thing that is important for me … (Service user 1).*

Others expressed further concern about equity in the use of technology and about service users who may be left behind:

> *Well, for sure I have already expressed a certain worry in terms of the technology that is being deployed. It's a good technology, "user friendly" for people who are still young, with telephones, QR codes, etc. But there are still many young people … who would have a lot of trouble using this, QR codes (Service user 5).*

Service users described the importance of creating safe spaces where they could speak up on issues:

> *Yes, it is important that the patient feels comfortable saying things. There can't be "backlash" in the interventions if someone complains, and afterward they don't feel comfortable (Service user 2).*

A family member reflected on ensuring full representation of service user voices, even when most feedback was positive and service users seemed satisfied, how to prevent biases and attend to the needs of service users less apt to express their opinions or whose experiences diverged from majority opinion:

> *I always see that it may be biased in the end, you know. Even if 90% of our clients are satisfied, this may be because people who weren't satisfied didn't answer … (Family member 1).*

Overall, service users were strongly on board with digital tools, welcoming the "technological leap" (Service user 1), with another service user underlining that service users are "in permanent contact with technology, which is instinctive for us" (Service user 2). Moreover, only service users addressed the conditions for successfully integrating digital tools, emphasizing measures that would make their peers more amenable to completing surveys. One noted that service users would have more ideas and be more "mentally prepared" when informed prior to meetings with providers or others that a questionnaire would be offered. They also requested better explanations of questionnaire concepts (Service user 2). Others noted the need for service users to better understand the importance of participation:

> *It would be important to inform the service user about the purpose of the survey … how services are useful, and to demonstrate that their opinions can make a difference in improving care. It is also important to state this in advance … (Service user 3).*

As another service user emphasized regarding meaningful participation of service users in RLHS data collection:

> *… the participation of users needs to be meaningful enough that the findings represent something reliable, not just summary, or partial findings that lack credibility. Youth participation is central (Service user 4).*

How the RLHS maintains and promotes learning, innovation and discovery

Stakeholders across the board were enthusiastic about participation in capacity-building activities. One psychiatrist characterized SARPEP as a "community of psychiatrists and carers meeting for the first time to discuss problems. Before, this did not exist" (Psychiatrist 2).

Capacity-building activities addressed practical issues, reassuring stakeholders about the RLHS:

> *I find (them) super pertinent because, again, I find that this is where the learning system really comes to life; it's okay to see that I have a gap, but how do I improve on it (Manager 1)?*
> *Sometimes I say to myself, 'heck, are we the only ones functioning like this?' … So, when we met, I said to myself, 'Okay, my reality isn't so different from that of other regions or teams.' So, when we met maybe twice in the past year … I found that it normalized our challenges as well as our successes, and the organization of our services. It was pleasant (Team leader 6).*

All service users felt welcomed at capacity-building activities and encouraged to share their ideas:

> *I found it very respectful. I knew some people when I did the meetings … I wasn't alone in my corner. I didn't feel isolated. I felt really accepted by the others. I have only positive points to make … Listen, I gave my opinion many times … I said what I think. I asked some very frank questions to certain people (Service user 5).*

A family member added: "it's a plus, plus, plus … It was a good experience" (Family member 2).

Psychiatrists and managers commented on how SARPEP helped promote learning and innovation regarding quality care in EIS. As a psychiatrist suggested:

> *SARPEP gave legitimacy to the entire implementation process for EIS and shed light on the Quebec EIS guidelines written by the Ministry. It's as if, at least symbolically, it signals a new tendency, a kind of accountability, I would say. It puts the managers in front of a structured project, for which there were objectives to be met … from my point of view, it contributed to the implementation of programs that are well structured, that work well and are useful (Psychiatrist 2).*

Finally, the findings suggest that SARPEP succeeded in creating a learning community, although for newer staff this was not always obvious:

> *I think there is a nice feeling of community. There was a nice collaboration in meetings. All the EIS representatives spoke about their different realities. A lot of stuff was brought up by patients, psychiatrists, providers, and case managers (Service user 2).*

Only a couple managers noticed that the early intervention for psychosis community in Quebec included many "communities of practice"; and that SARPEP is "one element among many" (Manager 4), showing the importance of effectively integrating SARPEP within the various Quebec initiatives:

> *Within the PPEP [Programmes pour premiers épisodes psychotiques – Quebec acronym for EIS] context, we have so many communities of practice. There is AQPPEP, then there are meetings of team leaders with the Ministry's National Centre of Excellence, there is SARPEP, there are lots of things. I am not sure whether SARPEP brings a community of practice, as such. It is one element among so many others. Nor am I sure whether people can separate very well what belongs to what … (Manager 4).*

How to sustain and improve the RLHS over time and the future of SARPEP

Stakeholders expressed interest in developing training resources to support continued data collection and in disseminating information to make SARPEP better known in their networks:

> *Basically, SARPEP should be better known to clinicians, managers, and higher-level managers, even to the general management (Manager 3).*
>
> *We must sensitize those responsible for the program in the hospital administration about the importance of this type of activity. So, we really must continue to engage these people in the process. And there, I think, it is important to utilize the Quebec mental health plan as a lever for SARPEP (Psychiatrist 1).*

Team leaders expressed a desire to involve various stakeholders (clinicians, service users, family members) in data collection:

> *If clinicians were also more involved in data collection, that would perhaps make more sense, and would become a real team mobilization project. I think it would be easier to get the data, perhaps on a day-to-day or weekly basis, and the entire team could be involved, rather than just having the team leader enter the data (Team leader 6).*

Several stakeholders favoured the extension of SARPEP:

> *If we put SARPEP in all Quebec EIS, I think that would be good, but, again, having the tools [information technology tools and support] so that utilization will be easier (Manager 4).*

Others, including service users, viewed extending SARPEP as well aligned with their interests:

> *Yes, because it gives patients a certain usefulness when they come. It allows them to regain a clear understanding of the importance of treatment (Service user 1).*

Asked about key learning from the project on how to improve EIS services, service users, family members and team leaders identified integrating peer support:

> *For sure, the development of peer support … will be very important for the future development of EIS (Service user 4).*

One family member said: "… psychosis affects everyone, not just the person, but the family, the entourage, a lot of people. And I think the service offered wasn't broad enough" (Family member 2). Managers also called for better engagement with families and their inclusion:

> *Well, do families have a space to propose improvements? I think that this is information we would like to have, as managers anyway ... We have patient partners ... we have, or will have, family partners (Manager 2).*

A service user provided the last word on priorities for SARPEP in the EIS:

> *Whatever the digital tools, the research, most important is that the person remains at the centre of the project, that the opinion of the person who receives*

> *care continues to be considered, and that s/he be considered a whole person with full potential for recovery (Service user 3).*

Discussion

In response to increasing public expectations of evidence-based and patient-centred healthcare, the RLHS represents a new paradigm for revamping health systems to achieve evidence-based, patient-centred care grounded in safe, timely, efficient and equitable practices. Yet very few RLHS have been developed or evaluated in the mental health context. The SARPEP project created one of few RLHS in EIS for psychosis worldwide [59, 47], and the first in Canada.

This study is the first to our knowledge to present qualitative findings on RLHS implementation in EIS. From the mixed-method SARPEP project, this paper describes experiences and insights of stakeholders involved in the design and two-year implementation of the Quebec RLHS in EIS for psychosis. Overall, the findings confirmed that the EIS accepted and highly valued the introduction of this innovative, measurement-based, digital system supporting the routine collection and sharing of program-level data within a RLHS. The RLHS also succeeded in implementing capacity-building activities and in creating a learning community where all SARPEP stakeholders, particularly service users and families, felt welcomed and motivated to target areas of improvement in services. Yet, at the same time, focus group participants expressed a variety of positions, experiences, knowledge and sometimes divergent opinions in relation to core indicators, for example, the concerns of clinicians and family members for symptom reduction and clinical outcome data, while service users focused more on quality of life and issues of personal well-being. Remarkably, participants commonly endorsed the necessity of a holistic approach to care that prioritized rapid access to services, while near unanimous convergence also emerged on the pressing need to integrate peer support and family peer support into EIS as SARPEP moves forward. This could be the result of the capacity of our RLHS to bring together different perspectives, give voice to persons with lived experience and emphasize this expertise as very relevant to service improvement.

The importance of timely and effective treatment underlined by all stakeholders in these findings represents a crucial element in EIS, given evidence that early intervention can lead to better long-term outcomes for individuals experiencing psychosis. EIS are designed to provide comprehensive, phase-specific treatment during the initial stages of psychosis [60], and individuals who receive early intervention are less likely to experience prolonged episodes of psychosis and more likely to achieve better social and occupational outcomes [61, 62]. SARPEP's focus on rapid learning and adaptation of services can enhance the responsiveness of EIS, ensuring that interventions are tailored to the evolving needs of patients and addressing the critical factor of maintaining engagement and improving outcomes [63]. The emphasis on engagement and therapeutic alliance in this study corresponds to pivotal themes in the literature on early psychosis, as the establishment of a strong working alliance between clinicians and patients was associated with better treatment adherence and outcomes [64, 65]. Similarly, the importance of peer support and a client-centred approach for promoting patient engagement during the initial stages of treatment is well documented [65, 66].

Stakeholder views on the key indicators, technologies for data collection and feedback

Study participants viewed the eight selected key indicators as highly relevant and useful. Access to care stood out as most consequential for recovery, followed by service user and family satisfaction. For some, maintaining quality standards depended upon ensuring service intensity (engaging/training staff; appropriate provider–patient ratios). Participants relied on the RLHS to boost their capacity to capture and monitor precise indicators aligned with evidence-based and recovery-oriented practices (Indicator 7) and patient-reported outcomes (e.g. self-evaluation of recovery dimensions) (Indicator 8). Participants found the selected indicators meaningful (Fig. 2) but disagreed somewhat on the ease or difficulty of collecting related data (Fig. 3).

Regarding the three technologies for data collection, aggregation, analysis and visualization, SARPEP stakeholders considered the REDCap digital platform as effective overall, although challenges persisted for managers and team leaders around dedicated time and resources for data collection. The much-appreciated graphical feedback allowed them to evaluate clinical performance, celebrate good results with staff and set new objectives. Uptake of the satisfaction questionnaires by service users, whether using "Happy or Not" terminals or REDCap, was somewhat weak, provoking considerable discussion among stakeholders on how to encourage systematic patient self-assessment and service evaluation practices. Psychiatrists and clinicians expressed concerns about biased results favouring extreme satisfaction/dissatisfaction with services. Extended discussion by providers, service users and family members addressed issues around competence and comfort with technology, the full representation of service user voices and equity regarding access to digital tools and skills-building, so no service user would be left behind. Service users, families and psychiatrists advised careful consideration of ethics and data security in shifting to a culture of measurement and in using digital technologies. Most crucial was the common concern for service user and family satisfaction, particularly in relation to the urgent need for more peer support and family engagement in EIS.

Reflections from the Lessard learning health system dimensions

Our findings also reflected the five dimensions of the Lessard et al. [53] LHS introduced above. Like other programs inspired by the LHS vision, SARPEP identified as primary objectives safe, high-quality services [53, 67, 68] and better patient outcomes, goals that were achieved according to participants. For instance, all 11 EIS started to collect and share data on the indicators, improved their measurement-based practices and committed to improve data quality and administrative/clinical practices. Moreover, the deployment of technologies by EIS demonstrated the capacity of the RLHS to support services and stakeholders, including service users and family members, as competent and equal partners in program design and evaluation activities [69].

Regarding the social dimension, and contrary to the view that successful RLHS implementation implies heavy data collection using sophisticated digital platforms and software, our findings supported a growing body of research suggesting that access to an integrated data platform is a necessary but insufficient condition for a successful LHS [34, 70]. Participants placed great importance on a social dimension, in the emergence of an active learning community and sense of belonging, spearheaded by SARPEP, which enabled EIS to compare practices and learn from each other's strategies, activities and procedures. Lessard [53] also proposed a culture of continuous learning, citing transparency, collaboration, teamwork and innovation as essential [71, 72]. The core elements needed to generate this culture include shared decision-making processes, alignment of stakeholder goals, requisite clinical and analytic expertise and appropriate principles of governance and leadership [73]. SARPEP stakeholders appreciated this new community for sharing both problems and solutions, while adding credibility to their work and strengthening their representations to decision- and policy-makers.

Empowering the social dimension, the technical dimension of the RLHS involved harnessing the digital infrastructure, designed to support data gathering, sharing, visualization and learning, to guide a shift in the healthcare ecosystem toward quality improvement and innovation. As findings described, the need for reliable and analyzable health data met with challenges: for example, making the REDCap platform and "Happy or Not" terminals more accessible and appealing to service users by introducing flexible digital solutions (QR code). Technical issues involving data lifecycle management and verification, mainly at the beginning of the project, and also the lack of time to changes practices between the data collection cycles reported by the clinicians and managers, ultimately resulted in a lengthening of the data collection–feedback–capacity-building cycles from 3 months to 4 months, allowing for more adequate time for implementation and addressing challenges related to lack of time and resources for service providers, who recognized the need to involve multiple people in real-time data collection and modification of practices. Other studies have described similar challenges [74–77]. Overall, service users and family members accepted both the short and long satisfaction questionnaires well, although their level of use (adoption) varied. Motivation among all stakeholders to participate fully in the RLHS also remained high, fostered by their sense of belonging to a movement nourished by a community of practice and recognition that the RLHS created the capacity to measure important indicators and bring about improvement.

The scientific dimension focused on innovations for improved health outcomes [34]. According to Lessard [53], this dimension incorporates social and technical elements of the LHS into a *continuous learning circle that moves from data aggregation and analysis to interpretation and practice change*. New data are generated for integration within the learning system. SARPEP promoted discovery, revealing practice gaps (e.g. lack of peer support workers in Quebec EIS), while informing Quebec EIS guidelines related to the anticipated incidence of new cases by region, which prompted funding adjustments for human resources; in addition, the modification of clinic opening hours based on available resources while maintaining flexibility and easy patient access for regular appointments or crises. Supported by the Quebec Ministry, SARPEP will embark on a larger-scale implementation, adding two to three waves of EIS to the original 11 and aiming to include all 33 Quebec EIS within approximately three years.

SARPEP has also inspired new research projects and collaborations. Researchers have proposed a CBT implementation study, using the RLHS infrastructure for data collection on EIS practices and participant evaluations, the LHS media library for training, community of practice knowledge exchange sessions and service user evaluations. Second is a cognitive remediation project that integrates user self-assessments into the REDCap platform and features a co-designed, stepped care intervention with service users, and capacity training for clinicians. PAIRPEP is a third ongoing project on peer support and family peer support implementation involving the entire RLHS system. PAIRPEP engages multiple RLHS stakeholders in partnership with local peer support organizations. The project also features a digital intervention (DIALOG+) for peer support workers and digital training using avatars.

Finally, the ethical dimension in RLHS is often unaccounted for [53], although preliminary work has led to a proposed ethical framework for RLHS activities [78]. Our study contributes to this area, especially in revealing the strong interest of service users and clinicians in preserving confidentiality and data security. Service users also expressed concerns about inequities in accessing digital technologies due to lack of skills or economic deprivation (e.g. youth homelessness). One peer support worker was assisting service user participation by helping them complete satisfaction and recovery self-assessment questionnaires. Findings strongly suggest that the Quebec RLHS is advancing toward a truly participatory and inclusive EIS ecosystem.

Limitations

The strengths and limitations of this study should be noted. SARPEP stakeholder engagement and co-design with ongoing input throughout the implementation period was a definite strength, as was data collection using stakeholder-specific focus groups. Member checking, a full review of study findings and contents by study participants, was also employed. Among the weaknesses of this qualitative evaluation, the fact that participants did not include family members of service users currently receiving care in the EIS should be underlined. The four family members actively involved in the SARPEP project (from design to implementation) were invited to attend the focus groups, and only two attended. However, as the focus of this study was on implementation of the SARPEP project, we considered the inclusion of service users and family members who were research partners as more pertinent to the composition of focus groups than others. Similarly, six former service users actively involved in the SARPEP project were invited to the focus groups, but only three attended; but only three service users currently receiving services were invited, and all attended. Moreover, we did not recruit persons who chose not to use our platform or be involved in our RLHS, which could be seen as a limitation … which could be seen as a limitation as their participation may have added information on how to make the platform more acceptable … on how to make the platform more acceptable to those who did not want to use it as actually organized. Therefore, while our sample represented the majority of those very involved in SARPEP, these participants may not have fully represented the service user population for the 11 SARPEP sites. Moreover, to protect the confidentiality of study participants (many of whom were still active members of the SARPEP project), this manuscript did not present demographic information, a further limitation of this study.

Another limitation affecting the first phase of SARPEP was our inability to provide service users and family members with graphical feedback due to ethical and technological issues around confidentiality. Thus, we were not able to gather information on data visualization for those users.

For the SARPEP research, we dedicated a full manuscript to the qualitative results given the richness of the data, even though mixed methods studies usually entail a simultaneous discussion of both qualitative and quantitative findings (convergent analysis). A future paper presenting a convergent analysis of qualitative and quantitative findings from the SARPEP project is planned, following the completion of further quantitative analyses.

A few reflections on the implementation of this project, sharing lessons learned, could possibly inform future research evaluating similar projects. The 2019 coronavirus pandemic (COVID-19), which seriously disrupted mental health service delivery at a crucial juncture for development of the SARPEP project, also brought a few positive factors for SARPEP. Indeed, the general shift to digital interventions, frequent use of virtual meetings and the felt need for better training in the use of technology probably raised interest and motivation for the SARPEP project. Staff turnover, greatly exacerbated by the COVID-19 pandemic as policymakers asked health organizations to concentrate human resources toward pandemic-related needs, was another issue encountered, occupying managers' time with hiring new staff and team leaders, and training them. As well, although SARPEP tried to show some flexibility, allowing a few weeks for data collection around the due date and providing support to the team leaders for data collection, the data collection period was time sensitive, making it difficult for team leaders to gain adequate experience with the RLHS, and possibly shaping their perceptions of the new technology and their recommendations. Accuracy in data collection was sometimes a challenge. To overcome these issues, we provided common methods of data collection using electronic tools shared with the 11 EIS that included clear terminology/definitions and instructions on how to measure indicators within the REDCap questionnaire itself. These solutions were developed over the course of the first year and improved over time based on stakeholders' feedback. Resource and funding scarcity were also ongoing issues, both long-term funding for the RLHS itself and funds for conducting its ongoing evaluation.

Finally, an important step that the SARPEP stakeholders identified was the need to develop practical guidelines for a RLHS for EIS to support effective implementation. Following the pilot project described in this paper, our team has undertaken other projects, including consensus-building activities where multi-stakeholder groups developed future recommendations regarding an RLHS for Canada.

Conclusions

This study described implementation of the first RLHS in early intervention services for psychosis in Canada, confirming the acceptability of the approach for promoting evidence-based care and measurement-based practices in EIS, despite initial challenges in deploying the technology and integrating data collection into routine care. The RLHS creates a welcoming community for learning and improvement. The findings support a range of provincial policies (system integration, healthcare monitoring, health informatics solutions, etc.). Most importantly, SARPEP has advanced our understanding of how the RLHS may be used and implemented in healthcare services, and lays the foundations for extending this paradigm to other jurisdictions where existing EIS services are located, in Canada or elsewhere. Sharing common measures used in RLHS operating in different provinces or countries, as a wider community of practice, may allow us to compare the impact of health policies and provincial health systems on the implementation of evidence-based practices.

Acknowledgements
The authors gratefully acknowledge the service users, family members and clinical staff working in Quebec early intervention services for their involvement in the SARPEP project and focus groups. The authors also greatly appreciate the contributions of Camille Arbaud, Kevin MacDonald and Judith Sabetti (alphabetical order) for their support in data collection, analysis, manuscript writing and formatting.

Author contributions

The researchers (A.A.B., S.I., A.L., M.F., M.A.R. – alphabetical order) designed the study. Researchers (M.F., M.S.S.) analyzed the data and developed the standardized code book. At the writing stage, the quotations were translated into English (Judith Sabetti), with oversight by K.M. and A.A.B., who are fluent in both languages. The principal investigators (A.A.B., S.I., A.L., M.F., M.A.R. – alphabetical order) reviewed and refined the themes and subthemes after exposure to the various analytical phases, including meetings to discuss previously shared analyses. All authors elaborated drafts of the manuscript and reviewed the final manuscript.

Funding
This project is funded by the *Fonds de recherche du Québec-Santé* (program name: *Données de recherche en contexte réel—Partenariat Innovation-Québec-JANSSEN—Volet Schizophrénie—Cliniques intégrées en santé mentale dans un contexte réel*, grant no. 284385). The aforementioned funding agency (which is the Quebec governmental health research funding agency) was not involved in the design of the study or data collection. Dr. Ferrari holds a salary award from the Fonds de Recherche du Québec–Santé.

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to privacy and confidentiality considerations but could be available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The research ethics board of the Centre de Recherche du Centre Hospitalier de l'Université de Montréal approved the study in December 2019 (reference: 19–282 and MP-02–2020-8627), followed by institutional approval from all 11 participating sites. Individuals provided written informed consent before participating in the focus groups. Only service users and family members received compensation, whereas other stakeholders participated during regular work hours.

Consent for publication

All participants consented in their consent forms to anonymized and de-identified publication of their data.

Competing interests

The authors declare no competing interests.

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Received: 4 April 2024 Accepted: 22 December 2024

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