Inter-Establishment Complex Musculoskeletal Care Pathways in Montreal: Timeline of a Collaboration Involving a Research Team Within a Continuous Quality Improvement Initiative

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ABSTRACT: Children and adolescents with complex musculoskeletal conditions may receive health care that requires at least 1 transfer between 4 specialized pediatric establishments in the Montreal region (Québec, Canada). This may result in challenges in navigating the system. A collaborative approach, aiming to make the inter-establishment care pathways seamless and to improve the integration of musculoskeletal health services, brought together key stakeholders including a research team. The aim of this paper is to describe the timeline of the collaborative approach's key milestones and activities and, more specifically, to describe the context, process, and outputs of the involvement of researchers in support of a continuous quality improvement project based on an integrated approach. The descriptive timeline was constructed from a qualitative document analysis of the project-related gray literature (n = 80 documents) and was validated and interpreted with key stakeholders. The results showed how the collaborative project was set up and operated, as well as what solutions were developed and implemented. The strategies on how the research team was involved in the integrated approach in addition to its research activities were also described. Conclusions suggest practice recommendations for creating change processes by integrating research, service evaluation and clinical audit into quality improvement projects.

KEYWORDS: Access to specialized care, navigation, fragmentation of care, continuity of care, inter-establishment transfer, collaboration, integrated pathways

Background

Each year, a few hundred children and adolescents in Québec receive musculoskeletal health care that requires at least 1 transfer between 4 specialized pediatric establishments of the Montreal region. These inter-establishment transfers are necessary because highly specialized care or services are only available at certain establishments. Additionally, some surgeons have privileges to practice at more than one site and thus, patients access services at more than one establishment depending on their needs. These 4 establishments involved include: 2 general tertiary pediatric hospitals, 1 affiliated rehabilitation center, and 1 private hospital providing only specialized pediatric orthopedic care that is part of a large international group of hospitals and healthcare sites. All of the participating establishments offer services to the population of Québec, a

Canadian province, in which an estimated 1.8M individuals are aged between 0 and 18 years old.

The ability to access multiple pediatric establishments provides a wealth of expertise available for patients and their families, but if ineffectively coordinated, the transfers can cause fragmentation of care, such as lack of relational continuity in care, poor transmission of medical and personal information, duplication of tests and examinations, and long delays for services.[1-3] These drawbacks can negatively impact the health and quality of life of the patient and the adults responsible for the patient (caregivers or parents), potentially resulting in deterioration of health, increase in care burdens, insecurity linked to lack of knowledge regarding available resources within the establishments, complications in family organization, and additional costs. For the health care providers, the management

of transfers also represents important challenges such as increased time and effort to find and access patient information, difficulty with patient follow-up, absence of feedback along the complex pathways, absence of standardization in healthcare providers' roles, as well as different admission/discharge criteria and information management procedures.

Therefore, these 4 pediatric establishments identified a need to improve inter-establishment care pathways to become seamless while enhancing the patients' experience, as well as the safety, timeliness, and efficiency of interventions in order to improve the overall quality of care.

General overview

The **Patient Trajectory** project ("Project") was developed, aiming to optimize these inter-establishment care pathways and to improve the integration of musculoskeletal health services in functional continuums that support the needs of the patients, and of their responsible adults, over the entire perisurgical episode of care: from home to hospitals to home. It was implemented as part of a larger collaborative approach ("Initiative") among the 4 establishments, spearheaded by a private donor with the specific intention of catalyzing collaboration between these establishments, supplemented by funding from the establishments' foundations. The Initiative's orientations are sanctioned by an executive committee that includes representatives from the administration, clinical, and rehabilitation levels of each establishment, parent-partners, and the Initiative manager (third author). It aims to develop numerous inter-establishment collaborations to improve the experience of care for young patients with musculoskeletal disorders requiring complex care.

The Project (directed by the sixth author) thus aims to promote the seamlessness of care processes, ensure the circulation of information, and reinforce the commitment from the 4 participating establishments to deliver patient-centered care with the objective of improving quality of care. This comprehensive approach primarily focuses on improving the care experience of patients and their responsible adults by facilitating their care pathway and ultimately building their confidence in the healthcare system. This is achieved through facilitating the management of events in the care pathway, providing useful tools to both clinicians and families to ease care navigation, and encouraging family participation.

The Project was conceived in 4 phases:

- Phase 1—Diagnosis of current pathways and challenges
- Phase 2—Co-design and operationalization of solutions to meet the challenges observed
- Phase 3—Implementation of retained solutions
- Phase 4—Impact assessment and adaptation of the implemented solutions
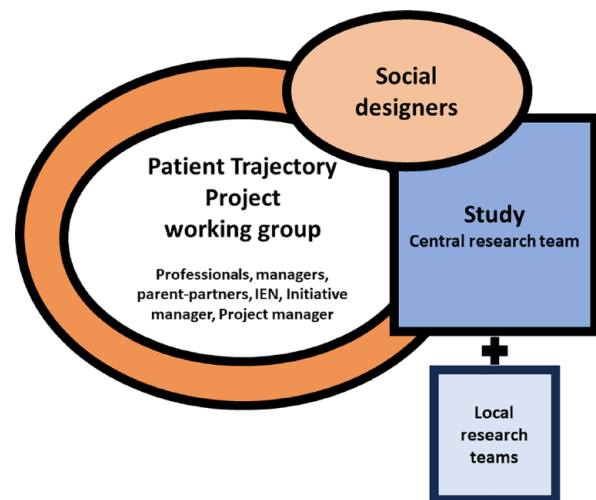
Figure 1. Governance structure of the Project. IEN: inter-establishment navigator.

The 4 phases were carried out by an interdisciplinary group (professionals, coordinators, and managers in nursing, surgical, and rehabilitation services, parent-partners, a new role named "inter-establishment navigators (IENs)," etc.) from the 4 establishments and adopted an integrated approach that also involved a research team and a social designer cooperative (Figure 1).

The first author of this paper was invited to join the team to participate in research and evaluation planning, such as identification of indicators and metrics to document current, and eventually redesigned, pathways. She was known to the 4 establishments, as she worked for 20 years with some of their teams, and especially as the leader of a large survey in southwestern Québec on the pathways of care for scoliosis patients.[4-6]

Indeed, a research protocol ("Study") was integrated as part of the approach proposed by the Project to assess the harmonized inter-establishment pathways in a real-time context. This Study aimed to identify the challenges of the current care pathways (by the collection of field data in Phase 1, since the challenges observed in the inter-establishment pathways had not been documented and/or very partial data was available), to share this data with the group as a support to the co-design process (Phase 2), to monitor the implementation of the retained solutions (Phase 3), and to evaluate the effects of these implemented solutions on patients, responsible adults, professionals, organizations, and the health system (Phase 4). The addition of social designers supported the process of gathering data on families' experiences (Phase 1) and the co-creation process and the design of solutions (Phase 2).

Objective

The aim of this paper is to describe the timeline of key milestones and activities of researchers within the collaborative approach of evaluating solutions to the problem of fragmented

healthcare pathways that involve inter-establishment transfers for young patients with musculoskeletal disorders requiring complex care. More specifically, we aim to describe the context, process, and outputs of the involvement of researchers as a support to this continuous quality improvement project based on an integrated approach.

Methods

For this article, we relied on a qualitative descriptive design[7,8] which helped in developing the main timeline of key milestones and activities involving the research team and their collaborative approach. The timeline was constructed with the use of the grey literature[9,10] from the Project and from the Study by the first 2 authors.

The grey literature (listing available on demand) that was consulted in this qualitative document analysis consisted of:

- Minutes of the Project meetings (n = 11) as well as pre-Project meetings (n = 3)

- The research protocols (initial and amended versions) (n = 5) and the Study's grant application (n = 1) and annual grant reports (n = 3)

- Press articles (n = 5)

- Working papers (ex. workshop material, mappings, etc.) (n = 29)

- Presentations prepared to support the team meetings (n = 11)

- Conference abstracts (n = 4), research seminars (n = 5), and research posters (n = 3)

The documents included were considered relevant as grey literature if they met the 2 requirements presented in Garousi et al: expertise and outlet control.[9] These documents were produced by stakeholders with recognized expertise in their field of practice and the context of the creation of these documents is transparent and retraceable.

Data from the documents were analyzed following a qualitative content analysis.[11,12] First, key moments in the timeline were identified by the second author and validated by the third author as central moments of the process. Subsequently, the research team identified elements to be identified for each timeline category: people and resources, procedures, actions, and interactions as well as outputs and results concerning the involvement of the research team in the development of a collaborative approach for harmonized inter-establishment pathways. Content extracted from the documents by the first 2 authors was coded and thematized based on these elements according to the key moments in the timeline.

We explored the meaning of this information: (1) by linking it to contextual elements[13]; (2) through validation of the change processes with the manager of the Project (sixth author), the manager of the Initiative (third author), the founder of the social designer cooperative (fourth author), and the IEN involved in field observation (fifth author); and (3) by using the definitions of Backhouse and Ogunlayi[14] for the change processes related to quality improvement and the framework of Baxter et al[15] for new models of integrated care.

The validation process was done through individual interviews with stakeholders involved in the Project where the model of timeline was presented and in which the research team asked for precision regarding elements of the timeline not covered in the grey literature. Subsequently, the timeline model was presented to other stakeholders involved in the Project in a meeting for validation, notably regarding the accuracy of the timeline.

Results

Four fundamental themes underpin the timeline of the Project and will be described in this section according to the context, the main processes for change, and the resulting outputs: (1) Consolidation of the Patient Trajectory project; (2) Mappings of the inter-establishment pathways from home to hospitals to home; (3) Identification of quick win solutions and IEN observations; (4) Sharing Study results and elaboration of broader "systemic" solutions.

Figure 2 illustrates the timeline of key milestones and activities of the Project.

(1) Consolidation of the Patient Trajectory project

Context of emergence of the issues regarding patient transfers. The Project emerged initially in 2017 as an informal "collaborative workgroup team," formed by representatives from the 4 establishments, to discuss which collaborative projects should be developed under the Initiative. The notion of inter-establishment patient transfers consensually emerged as the major concern and shared issue to be documented and addressed. These initial meetings led to the first official documentation of the Project in the form of preliminary mapping of the patient pathways, highlighting issues emerging in the context of inter-establishment transfers of patients with musculoskeletal conditions along the pathway of their surgical episodes.

Process of implementation of a multifaceted and integrated team. A signed agreement was put by the 4 establishments to concretely implement the Initiative (including several collaborative projects such as the Project). An Initiative manager was hired (third author) which facilitated the implementation of the overall Initiative's collaborative program, as well as the implementation of a governance structure with an executive committee and an advisory panel of patient-parent experts. The implementation of the Project's structure within the Initiative facilitated the allocation of a dedicated budget and
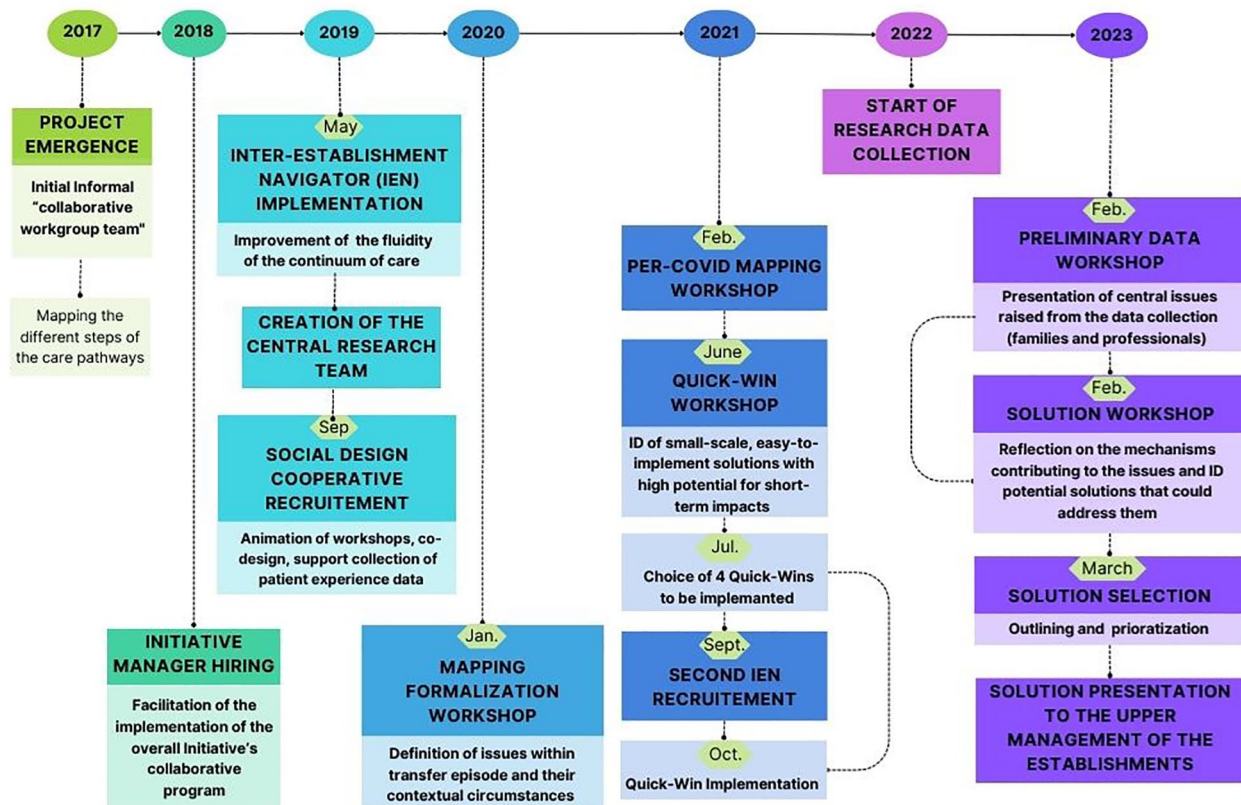
Timeline of the Project

Figure 2. Timeline of key milestones and activities.

resources for functioning. The Project's formal structure and organization was consolidated between 2018 and 2019, with the nomination of qualified individuals by the management of the 4 institutions.

The Project benefited from a new role that was created as part of another structuring project of the Initiative: the "Inter-establishment Navigator" ("IEN"). As a shared pivot professional, the IEN assisted the clinical coordinators, allied health professionals and staff managing patients across establishments and ensured that users were aware of the services available for their complex conditions. The implementation of such a position preceded the official launch of Phases 1 and 2 of the Project.

Outputs. The steering structure of the Project, detailed in Figure 1, is composed of different actors with defined roles:

- The manager of the Initiative provides guidance, support, and orientation to all teams' members and stakeholders under the Initiative. This position was established as "neutral" and "independent," serving the 4 establishments as an unbiased, objective-driven mediator for any conflicts arising.
- The manager of the Project's role is to oversee its strategic planning, to arbitrate on any major decisions to be

taken in agreement with the group and to represent the Project with external partners.
- Managers and professionals from the 4 establishments are also part of the Project as representatives of their settings to convey the experience of the concerned units or departments (as identified from the preliminary mapping of the patient pathways) and to contextualize findings so that the Project can identify both cross-sectional and site-specific issues/solutions. Their involvement ensures that the group's reflections are deeply rooted in the local clinical context.
- The IEN brings together cross-sectional views of the various environments, including external partners in the provincial health system, sponsoring a global view of the common issues observed. The IEN also supports the improvement of processes and procedures. The IEN that joined the Project was instrumental as facilitator in introducing the Study to staff and supporting their understanding of their potential participation due to the professional relationships they developed with the clinical, managerial, and administrative personnel of the partner establishments.
- A "central" research team (Figure 1), composed of the first author, a study manager (second author), 3 Master's students, and a research assistant was integrated in the

Project and obtained peer-reviewed co-funding for the Study from a provincial innovation program. The research team aimed to support the Project with evidence and a rigorous scientific approach in the group's reflections, the eventual proposals for improvements, and the evaluation of the implementation and impact of the solutions. It proposed a conceptual framework and surveyed families and professionals to identify current issues in the pathways, documenting instances of care fragmentation from administrative and clinical data. Additionally, local research teams (a local PI and a research assistant) from the participating establishments were assembled and trained. Notably, they collaborated with the central team to adapt the Study protocol to the local requirements and to conduct data collection.

- Two parent partners were also integrated as full members of the Project to bring the perspective of families who had the experience of care for their children in the participating establishments. In the context of the study, their role was notably to make sure that the data collection tools were appropriate for the target population (in terms of relevance, clarity, and literacy) and to contextualize the findings concerning the identified issues in the care pathways.

- Members of a social design cooperative were integrated in the Project as independent experts for the animation, facilitation, and moderation of working group workshops aimed at the co-creation of solutions to be implemented collaboratively within the partner establishments. Consistent with the integrated approach of the Project, the central research team and the cooperative exchange best practices according to their respective field of activities. In particular, members of the social design cooperative were integrated into the research team to support the Study in the collection of family experience data. To do so, they notably had to fulfill all the requirements from the evaluating research ethics board.

Overall, the multifaceted group—the managers and professionals from the 4 centers, the parent-partners, the research team including the local research teams, the social designers and facilitators like the IEN and the manager of the Initiative—is working in an integrated and cross-functional manner to achieve the objectives of the Project. For these stakeholders, the Project was an unprecedented opportunity to lead, design, and deliver change through interventions that address issues that were collaboratively raised and that may benefit their patients, units, establishments, and their practice.[16]

(2) Mappings of the inter-establishment pathways from home to hospitals to home

Context. In 2017, prior to the effective implementation of the Project, a first exercise of mapping the different steps of the

care pathways for different profiles of patients in each establishment was completed. This first exercise helped to identify the different units and services involved in patient management, from outpatient clinic visits and steps for preoperative assessment to postoperative care and planning for discharge. While these mappings were highly informative in determining how each of the establishments was handling the different pathway steps, the need to shed light on the circumstances specific to the transfers between establishments emerged, as these were identified as critical moments in the pathways where fragmentation of care may become problematic. In addition, 3 patient profiles on which the Project agreed to focus their work were identified. These 3 profiles are:

1. Surgery for spinal deformities
2. Surgery to the upper or lower limbs in patients with motor impairment
3. Rhizotomy surgery.

These profiles were identified because of the complexity of the care pathways: at least 1 inter-establishment transfer was experienced, patients consulted multiple service providers over a long period of time for changing needs, and they received care in different specialized service areas.[17]

Process. An in-person workshop with the members of the Project's working group was held in January 2020 with the goal of developing a consensual definition of these clinical profiles of interest and a consensual schematic definition of inter-facility peri-surgical care pathways used by these patients, from home to hospitals to home. Moreover, this workshop aimed to update the information contained in the mappings from 2017, fill in the information gaps for each of the pathways including timing and transitions related to transfers, identify perceived irritants, and raise issues noticed throughout the pathways.

During this workshop, following a general presentation of the 2017 mappings, 3 subgroups (1 per profile) were formed to discuss the pathways with a focus on the 4 main steps in which transfers of patients from one establishment to another may occur:

- Transfer A: from the outpatient clinic where clinical follow-ups and decision to proceed with surgery may occur to the preoperative assessment
- Transfer B: from the preoperative assessment to the surgery
- Transfer C: from the surgery to postoperative care
- Transfer D: from postoperative care and inpatient rehabilitation to discharge and return home

Participants identified issues that could arise during these key moments for the profile attributed to their respective subgroup, describing in their view the impact on patients and families, the impact on the process of care, and the factors that may be

related to each particular issue. The elements discussed in subgroups were summarized on sticky notes and displayed on large boards assembled by the 2 social designers (including the fourth author) and the first 2 authors, who all contributed as facilitators for the subgroup discussions. The content of the boards was subsequently discussed in a plenary session where all the participants contributed their input to each of the 3 mappings. A "debriefing" meeting was held 1 month later in February 2020 to consolidate and validate the information, and to refine the visual representation of the mapping to be taken into consideration by the working group. Pathway and profile-specific issues were highlighted as well as cross-pathway and cross-profile issues.

Outputs. This first mapping workshop was notably useful to define where the issues lay within transfer episodes and their contextual circumstances (fragmentation of care, service breakdowns from the perspective of professionals, duplication of services, etc.), to enable all stakeholders to share a common evaluation of the situation and ultimately to identify all together the areas where the Project should target its actions.

As this workshop had been held a few weeks before the advent of the measures surrounding the COVID-19 pandemic, members of the Project expressed in 2021 the need to update the mapping to reflect how the pandemic and the sanitary measures impacted the pathways as they had been described in the 2020 mappings. The IEN and certain members of the working group met with the people in charge regarding COVID-19 in the participating establishments to gather information on the specific measures adopted in the contingency plans of the individual establishments. A new workshop with members of the Project was held in February 2021 to review the pathway mappings in light of this information and to discuss potential changes that may have occurred in the pathways that should be integrated into the 2020 mappings, as some may subsist post-pandemic. The general conclusion to this workshop had been that the general mapping of the pathways did not undergo major changes as a result of the pandemic. The identified changes were:

- The implementation of transitory measures such as the need to perform COVID-19 testing before any transfer as well as routine testing at day 0, 5, and 10.
- Efforts to bundle preoperative appointments to limit the number of outpatient visits

- The agreement that 1 of the 3 surgical sites which is specialized in pediatric orthopedics could take over performing spine and limb surgeries in support of the 2 general pediatric hospitals

Regardless of the transitory measures, these changes were considered positive adaptations to the pathways that could be maintained in the peri- and post-pandemic era.

(3) Identification of quick win solutions and IEN observations

Context. Many contextual elements linked to the pandemic slowed down the activities of the Project and the Study until early 2022. Despite the delays for getting authorization for Study data collection for Phase 1, by 2021, the Project had already collected information that could be utilized to reflect on potential solutions, notably by the involvement of the IEN in the field. Thus, it was decided to hold workshops to develop "quick win"-type solutions, meaning small-scale, easy-to-implement (high feasibility) solutions with high potential for immediate/short-term impacts, while more systemic solutions would be developed later with research data as support.

Process. This process consisted of 2 workshops with the members of the Project working group. The first workshop was held in June 2021. In line with the mission of the Initiative for which taking patient experience into account is a major priority, issues identified previously in the mappings were reflected on by considering their perceived consequences on the continuity of care for patients and families. Categories of issues were defined on the basis of their potential impact on the 3 types of continuity: relational, informational, and managerial.[18-21] Discussions in sub-groups led to the identification of quick win solutions (more systemic solutions that were proposed were saved and stored for later use) that could potentially be implemented to address issues, based on experience, expertise, and knowledge from other contexts of practice. A total of 11 quick win solutions were identified in this workshop.

A second workshop was held in July to identify the 4 quick win solutions that should be implemented and to discuss the process of implementing them in the short term.

Outputs. The members of the Project decided to implement the 4 following quick wins:

QUICK WINS	TYPE OF CONTINUITY	DEFINITION	ISSUES ADDRESSED
Obtain consensus on a checklist of information to be transferred	Informational continuity	Development of checklists of what information needs to be transferred between establishments to ensure that relevant and more complete clinical information is exchanged across the pre- and post-operative continuum.	Disparity of information required by each center and incomplete data transfer.
Generate a responsibility matrix for information transfer in each department (coordinators, key players, other)	Informational Continuity	Identify triggers in patient care flow to obtain timely patient/family authorization for information transfer to ensure completeness of relevant transfer information. Identify responsible person in each center/department to obtain authorization.	Reports gathered before the signature of authorization cannot leave center. Therefore, missing authorizations prevent the transfer of information between establishments, which can lead to incomplete information in the destination establishment.
Enable remote access to records by physicians	Informational Continuity	Implementation of means (such as ID key or dedicated terminals) to enable physicians to access records remotely while providing care at a partner site.	Absence of a shared electronic medical record. Lack of synchronization between partner sites' information systems (for example, paper reports and medical imaging).
Clarification and dissemination of the admission criteria for the Intensive Functional Rehabilitation Unit	Managerial Continuity	Augment form with checklist of admission criteria. Explicit mention of admission criteria on the unit website and publicize the services provided by the rehabilitation unit to all relevant stakeholders (meetings).	Transfer request for patients not conforming to admission criteria in intensive rehabilitation which caused delays or actual refusals for admission.

One of the IENs was subsequently entrusted with the implementation of these solutions within the 4 establishments. Although not originally planned, this novel process was useful for the development of the co-design approach and the training of the group in this process, which was later to be used for reflecting on broader solutions at the 2023 workshops (described in the next section (4)). Concurrently, the workshops of summer 2021 served as a first step to sketch potential systemic solutions to be discussed in coming workshops. The outputs were also presented, in addition to the mappings, as the first deliverables of the Project to the Initiative executive committee and were useful in demonstrating the activity of the workgroup in the field.[14] It also allowed the Project to work independently from the Study to put forward the IEN's field observations. This response to an unforeseen situation also helped position the IEN as a central agent in the process of inter-establishment transfers.

(4) Sharing study results and elaboration of broader "systemic" solutions

Context. According to the original planning, Phase 1 was to make a diagnosis and to collect data so that in Phase 2 it could be possible to include some of the Study results in a co-design exercise for the development of solutions. As previously mentioned, the research data collection was delayed due to different issues mainly related to the COVID-19 pandemic and finally started in Fall 2022. Members of the social design cooperative and the research team conducted interviews with responsible adults of surgical patients from the different profiles. They were interviewed about their experiences of the 3 types of continuity in the pathways involving transfers. In addition, focus group data collection with the professionals involved in the transfers was conducted, which permitted the incorporation of the professionals' vision of the individual, organizational, and systemic barriers and facilitators to transfers. The latter were also questioned on their perception of interprofessional and inter-organizational collaboration in the context of inter-establishment transfers,[22] with the aim to develop a new research question.

On the basis of all the work carried out by the integrated team since the outset of the Project, the Study material was analyzed and summarized to support the group's collective reflections on solutions to facilitate the current care pathways to be subsequently submitted to the establishments for implementation.

Process. This process consisted of 3 workshops with members of the Project. The first workshop was held in early February 2023, facilitated by the social designers and the central research team. Preliminary data, notably from the interviews with family members, was presented in connection with the mappings

of the pathways, along with the observations of the professionals drawn from the focus groups. Ten highlights, which represent central issues raised by family members and cross-referenced with professional concerns, were presented based on the 3 types of continuity (relational, informational, and managerial) and each was discussed separately.[18-21]

A second workshop was held 2 weeks later, facilitated by the social designers with the use of a collaborative online whiteboarding platform, to reflect on the mechanisms contributing to these issues and to identify potential solutions that could address them. Following this second workshop, some members of the working group (a reduced committee) produced a summary of the discussions of the workshop, outlining 11 potential solutions to implement, grouped into 4 categories based on the level of effort required for implementation and the potential impact

of these actions on staff and/or on patients (solutions implemented in one establishment to be duplicated in others; solutions already implemented among the partner establishments to be strengthened; new inter-establishment projects; and new longer-term supra-institutional projects). Subsequently, the 11 solutions were presented to the Project working group in March 2023, a meeting in which members took part in a prioritization exercise and agreed upon 6 solutions to be presented to the upper management of the establishments.

Outputs. The 6 solutions to be prioritized focused on different aspects of the patient trajectory, such as empowering patients, providing tools for care coordination, improving liaison between pathway steps, etc. More specifically, these 6 solutions are:

SOLUTIONS	TYPE OF CONTINUITY	DESCRIPTION	ISSUES ADDRESSED
Two solutions to duplicate			
Early interdisciplinary meetings	Relational continuity	Ensure that one of the first appointments with families is with the majority of the professionals who will be involved with the patient in order to promote interdisciplinary collaboration within the care team from the outset.	A relational connection that is difficult for doctors to maintain on their own. Initiatives by caregivers are appreciated, but seemingly "ad hoc."
Postoperative follow-up call	Relational and informational continuity	A systematized call, made by a member of the care team, 48-72 hours after the child's hospital discharge during which families can ask questions, and whereby the provider can more easily identify their needs.	The hospital discharge was not always well-prepared. Information communicated to parents was incomplete. Parents often serve as guardians of informational continuity, but are not fully equipped to do so.
Two solutions to be strengthened			
Preoperative courtesy call	Informational continuity	A systematized call, potentially linked to the surgical appointment confirmation call, intended to provide the family with important practical information about the establishment where the surgery will occur and to ease the family's preparation for the surgery.	Available services and resources gradually uncovered or found over time (often untimely).
Role of the IEN	Managerial continuity	To emphasize and sustain the new position of the IEN and to make the role more visible so that as many people as possible can benefit from it. The scope of this role could be adjusted according to the needs demonstrated over time in order to support both professionals and families.	Coordination issues that create an additional burden for the families. A feeling of service breakdown at times of transition.
Two new projects			
Four-way exchange protocol	Informational and managerial continuity	Implement an agreement between the 4 establishments that would be signed early by the families and would allow the sharing of patient information between establishments at any time along the pathways, without the patient having to sign a specific authorization for information each time.	Parents often serve as guardians of informational continuity, but are not fully equipped to do so. Coordination issues that create an additional burden for the families. A feeling of service breakdown at times of transition.
Ad-hoc inter-establishment trajectory management committee	Managerial continuity	Create an interdisciplinary, inter-establishment committee that could take the form of a monitoring room and would meet regularly to discuss pathway issues encountered by families. This committee could both address emerging issues and follow up on the solutions implemented.	Coordination issues that create an additional burden for the families. A feeling of service breakdown at times of transition.

These solutions were subsequently presented to the upper management of the establishments and were perceived as pertinent and well-supported solutions with great implementability by the attendees. Discussions regarding their implementation are ongoing as of Summer 2023, in particular for the creation of the inter-establishment trajectory management committee, which would be the starting point for solutions implementation.

Discussion

Summary of contributions

In this paper, we formulated the timeline of key milestones and activities of a collaborative approach to diagnosed fragmentation problems in multiple pathways of peri-surgical care in pediatric complex musculoskeletal care. The group engaged in an inclusive evidence-based design process to elaborate solutions to improve harmonized inter-establishment pathways involving patient transfers between specialized care establishments, from home to hospitals to home.

This multiperspective collaborative work bridged a quality improvement project conducted by a group of health professionals, managers, and parent-partners with a research and evaluation Study involving a central team and local research teams as well as social designers within a larger collaborative Initiative. Working together, the collaborators provided several main contributions.

First, the group involved multiple stakeholders from the 4 participating establishments, since its inception. The whole team collectively and progressively developed a new culture of inter-establishment dialog and collaboration, led by the vision of involving and empowering patients and families and focused upon improving the response to expressed needs, challenges and perceived issues in these complex care pathways.

Second, the collaborative team achieved a clear and common understanding of the inter-establishment pathways, and, in particular, of the circumstances surrounding transfers. The identification of main issues expressed by the patients and families in relation to continuity of care and their experience resulting from the poor integration of services around inter-establishment transfers was conducted. The research team also brought into the discussion the perception of the professionals and managers of the 4 establishments in relation to barriers and facilitators to management of transfers and issues regarding interprofessional and inter-establishment collaboration.

Third, the group identified critical steps along the peri-surgical pathways as well as some "floating moments" between the main transitions when families feel they need more support and accompaniment. These include: preparation for the initial visit, time periods (sometimes long) between the visits where changes in the condition or in the well-being of the patient may occur or new questions may arise, the sometimes poorly anticipated and always stressful time for discharge to home, and insufficient coordination with local outpatient rehabilitation clinics, technical aid, and home care services.

Finally, the Project worked on the co-design of solutions promoting patients and families' empowerment and participation. The solutions that were elaborated by the Project rely on various organizational levers and borrow elements from different types of new care integration models.[15]

Two solutions focus on improving patient care directly through the adoption of strategies to anticipate problems and be proactive. The transfer to home in the postoperative period was identified as a very stressful period for families. The deployment of a postoperative follow-up call in all participating establishments should support families in the identification of their specific needs and promote equity of access for families who have more difficulty accessing services when needed after discharge. In turn, the follow-up has the potential to reduce readmissions and uncoordinated services utilization by allowing prevention or earlier management of potential complications. In the context of pediatric care, literature shows that post-discharge calls to gather information on adequate pain management,[23,24] to provide additional counseling and instruction to family members,[23-25] and to detect complications,[25,26] address postoperative anxiety and concerns and improve postoperative satisfaction.[24,27] In addition, the preoperative courtesy call provides an opportunity to create an initial connection with the new establishment. It may contribute to making the patient and family more informed, confident, and autonomous during the transfer. Although literature is dense on the importance of preoperative information sharing to reduce preoperative anxiety[28] and increase parent and patient satisfaction,[29] most information described in the literature refers to medical information, notably anesthesia.[30-32] To our knowledge, data is scarce about the importance of sharing practical and non-medical information in preoperative phone calls. Nonetheless, our preliminary results from responsible adult interviews showed that the sharing of such information during preoperative phone calls, although such information is available elsewhere, would have reduced the burden of the surgery process, notably for parents living far from the establishments. It is also noteworthy that evidence from such interventions is insufficient in the context of a surgical pathway involving an inter-establishment transfer.

Another solution implies a change in the system[15] by generalizing and systematizing the timely utilization of an authorization form for medical information transmission between the collaborating establishments. It is expected that this will reduce time spent managing the exchange of information and will reduce the administrative burden on families coping with the lack of informational continuity.

Two solutions call for changes in the way the staff are working.[15] First, the planning of an early interdisciplinary visit comes from the observation that the physician specialist is often the primary reference figure for the patient and their family between the different establishments during transfer. On many occasions, however, the needs of the families may also be relevantly addressed by another professional (eg, physiotherapist, social

worker, etc.). This solution facilitates complementary actions and enhances communication between professionals, ensuring consistent information sharing between professionals for better management of family expectations. Secondly, emphasizing and ensuring sustainability by extending the role of the IEN, who displays a strong and positive leadership presence and receives support from the Initiative governance to implement clinical and managerial innovations,[15] will facilitate knowledge sharing, mutual understanding, and liaison both within entities in the Project and beyond—that is, with relevant intersectoral actors who need to interact with patients and families.

Finally, the group proposed the creation of an inter-establishment trajectory management committee that will primarily monitor the 5 other solutions to be implemented in the field on the medium and long terms and make recommendations for process revision.

Synthesis of the role of the researchers with other components of the integrated collaborative approach

The Study team was integrated as part of the Project working group and stakeholders. They worked particularly on the evaluation of pathways (Phase 1), introducing conceptual frameworks, selecting indicators and measurements at different levels (patient, responsible adults, professionals, organization, and health system), and designing and testing interview grids. The Study team was also responsible for the careful planning of data collection, searching for additional funding, obtaining ethical approval to proceed, building and training local research capacity, and displaying flexibility for protocol adaptation. In order to support the Project co-design workshops of Phase 2 without interference in decisions, the Study paired with the social designer cooperative to provide service evaluation (with the purpose of generating information for local decision makers about the functioning of the services).[14] It also took advantage concurrently and consecutively of field observations from the IEN. The latter provide day-to-day data to draw a picture of how the services are provided and their alignment with recommended standards.[14] As appropriate, the Study team shared information with the Project members about published evidence or reported on best integration practices. In parallel, the research team derived new research questions[14] from the Project process by, for example, investigating the modes of interprofessional and inter-organizational collaboration in the context of transfers.

Strengths and limitations

This approach took advantage of opportunities offered by different process change methods mobilized in this Project, such as the IEN's field observation and service evaluation through the social designers' role to raise awareness about the need to consider the patients' perspective when defining and implementing solutions and services. Group integration was strongly achieved as illustrated by the timeline of key milestones and activities, the number and the diversity of documents that were collectively produced and analyzed for the purpose of this paper, and the coherent data-driven solution sets that were delivered. It is important to note that the Study team did not interfere in the decision process and the Project maintained its independence in decisions. Reciprocally, the research teams also kept their independence and autonomy in the conduct of the Study.

The study aimed to fill a gap in the literature on inter-establishment transfers, which is very limited when it comes to the study of transfers between specialized care facilities. It also contributes to pediatric care, a domain in which such studies are rare. In addition, the Study exemplifies how such an integrated approach may contribute to supporting health care professionals in their diverse roles, including accompanying patients and families in complex care pathways.

The Study encountered many obstacles, such as long delays in obtaining data, which may lead to a potential problem of timeliness of observations and risk of history or maturation bias in future impact assessment. In addition, the data collection process concerns the retrospective documentation of the family experience because of the inability to track the activities in the pathways in real time, notably due to the limited physical access to the participating establishments in the wake of the COVID-19 pandemic. This has reduced the opportunities for intervention in the field.

Lessons learned

The authors would like to share some lessons learned that illustrate what we would consider doing the same or differently in a future project. First, we would raise all partners and stakeholders' awareness regarding the research project timelines, which differ from quality improvement and are sometimes lengthy. This would be important to manage expectations from clinical and managerial teams and to better align the Project and the Study schedules.

Second, an essential key success factor was the selection of the Initiative manager, not only for her competency in management and her knowledge of the pediatric hospital environment (as she was previously working at the ombudsperson office of one of the participating establishments), but mostly for her collaborative leadership and vision, as well as her strong interpersonal relationship skills.[16] Many stakeholders acknowledge that proper selection of this individual led to the success of the overall Initiative to ensure ongoing engagement. Also, considering the invaluable contribution of the IEN to facilitate research protocol implementability and acceptability, it would have been preferable to involve these key resources more integrally and, at that, earlier in the Study.

Future projects involving an active participation of a research team in an integrated collaborative approach should consider distributing the activities between different participants with similar qualifications and characteristics to diminish the burden on individuals. Many professionals involved reported not knowing their counterparts in the other establishments who shared their roles and concerns with patient transfers. The

methods used, such as focus groups with professionals and administrative staff and codesign workshops, created opportunities to foster mutual acquaintance that will support future interprofessional and inter-establishment collaboration.

Conclusions

The timeline described in this paper shows that a collaborative approach involving key stakeholders, such as researchers, social designers, parent-partners, facilitators, health professionals, and managers, is an interesting model to develop integrated processes in the context of continuous quality improvement. It stimulates mutual understanding and knowledge-sharing between stakeholders for the ultimate benefit of patients. This paper also shows research team's involvement with the workgroup in parallel to their research activities, which allows them to remain independent while adapting an approach that leads to answers closer to the real needs.

Based on this experience, to integrate a research team into a similar quality improvement approach, we suggest these recommendations:

- Openness of all members of a working group to learn from each other.
- Dedicated and neutral project management.
- Flexibility, adaptability, and agility regarding the study design.
- The research team must keep a distance or a non-interference standpoint regarding the final decisions.
- While integrated in the continuous quality improvement project, the research team must keep its independence for protocol elaboration and for data analysis; it also benefits from the autonomy to explore new questions and develop new knowledge about complex care pathways.

The solutions presented in this paper are currently being discussed to be implemented in the 4 participating establishments as of Summer 2023. In parallel, the next steps of the Study will be to evaluate the implementation of these solutions and their impacts at the patient, responsible adult, professional, organizational, and systemic levels.

Research Ethics and Patient Consent

The present paper does not include research activities involving the recruitment of patients or any other human subject who requires consent. However, the *My Way/Mon chemin* was approved by the Research Ethics Board of CHU Sainte-Justine in two parts at their request. The first part of the Study describing the research activities of the Phase 1 of the Project was initially approved in November 2020 (MP-21-2020-2721) and was amended in April 2021 and in March 2023. Part 2 covering Phase 2, 3 and 4 was approved in March 2022 (MP-21-2022-3843). The involvement of the research team in the Project and the involvement of other members of the Project in the Study is described in both approved protocols.

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