



Partenaire de votre développement collectif

Report on the Impact Evaluation Process of the MUSCO Initiative

[translation of the original report]

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INTRODUCTION

MUSCO is a collaborative initiative between CHU Sainte-Justine, its Marie Enfant Rehabilitation Centre, the Montreal Children's Hospital and the Shriners Hospitals for Children - Canada, with the support of the Mirella and Lino Saputo Foundation. The goal of the Initiative is to improve the care and services provided to children with musculoskeletal disorders and requiring complex care, and their families.

The Initiative, which began in 2018 and will run for five (5) years, has a mission to transform the care and services provided to children and families. It aims to create synergy to improve patient care, treatment, and rehabilitation via a comprehensive and collaborative approach that aims to implement concrete and meaningful solutions to address the various issues faced by families.

The Initiative includes a portfolio of some twenty projects ranging from the recruitment of a shared resource person for the four (4) partner institutions, to the organization of events, to the acquisition of rehabilitation equipment and the development of educational technologies.

In order to document the effects of this innovative initiative, the partners wished to set up an evaluation process with the following two objectives:

- Draw up a collective assessment of the main outcomes of the projects deployed on site and draw lessons from these experiments.
- Document the progress made in relation to the partnership work (mobilization, collaboration, governance, etc.).

The expected results of this approach are as follows:

- To better assess the effects of ongoing experiments at different stages of their implementation.
- To inform decision-making and adjust interventions along the way.
- To encourage the mobilization of actors around the Initiative.
- To make its results known and valued by the different partners.

1. APPROACH

The general objective of the evaluation process was to identify the changes that the MUSCO Initiative contributes to for patients and their families, as well as in the practices of professionals.

The proposed evaluation approach focused on mobilizing the actors involved to achieve common objectives through a structured and participatory process.

One of the objectives of the participatory approach is to allow the stakeholders to take ownership of the process and to ensure that the evaluation process results in organizational learning. Since the ultimate goal of evaluation is to help decision-making, the evaluation process was designed as a vehicle for mobilization and dialogue with a goal of improving practices.

Finally, a participatory evaluation approach focused on the use of results was favored. The involvement of the stakeholders and the promotion of the expertise and knowledge generated by these actors aim to generate lessons learned and to put them into action throughout the Initiative and at the end of it.

To do this, an Evaluation Committee was involved in the various stages of the process. This committee was a reflection of the various committees that existed within the Initiative in order to enhance the expertise and knowledge of the various key players (stakeholders, partners, families, etc.).

The Evaluation Committee acted as a referral body for the evaluation mandate of the MUSCO Initiative. Its role was to:

- Validate the consultation objectives with stakeholders (families, stakeholders, decision makers, partners).
- Understand the methodology and contribute to its application (e.g., recruitment, mobilization, etc.).
- Participate in a co-analysis exercise based on the results generated during the interviews, in order to highlight the main achievements observed and the learnings generated.
- Participate in the elaboration of recommendations, based on the synthesis written by Niska.

The process took place in five (5) steps:

- Launch of the process and identification of what is important to know.
- Development of the Initiative's Theory of Change and evaluation strategy.
- Stakeholder consultation and data collection.
- Participatory co-analysis of progress, learnings, and challenges.
- Synthesis and recommendations for the Initiative's continuation.

2. EVALUATION STRATEGY

The evaluation strategy was built on the basis of the MUSCO Initiative's Theory of Change (see diagram in Appendix I). Thus, two (2) main paths of change and one (1) secondary path emerge in order to reach the ultimate goal of the Initiative. The three (3) long-term goals are:

- Patients and their families are supported to improve their quality of life, including a seamless experience across institutions.
- Communications and collaborations are optimized and become the norm.
- The MUSCO experience can be reproduced in other settings.

The strategy is therefore built around two (2) major components:

- The family component, which seeks to measure the effects of the Initiative on patients and their families.
- The collaboration component, which seeks to measure the effects of the Initiative on the professional and collaborative practices of stakeholders and collaborators.

2.1 FAMILY COMPONENT

EVALUATION OBJECTIVE 1

- **Measuring the quality of support provided/received: families supported, trained, informed.**

Does MUSCO provide a better understanding of families' needs, leading to improved practices?

Does MUSCO help strengthen the quality of support offered to families?

Methodology :

One (1) focus group: four (4) workers on-site involved with families, people who prescribe support for families (clinical services, social workers) in interaction with the MUSCO Inter-establishment Navigators (IEN) and research assistants from the Orthopedic Clinical Research Unit (URCO).

One (1) individual interview with a parent.

One (1) individual interview with an IEN.

EVALUATION OBJECTIVE 2

- **Measuring the quality of family/professional collaborations: listening to the families which results in real transformations in the light of what has been heard.**

Does MUSCO help empower families (capacity and opportunities for collaboration)?

Methodology :

Two (2) focus groups:

- Four (4) parents/patients: participants in the MUSCO workshops on the integration of patient-resources, patient-experts from the advisory pole, and patient-resources from the work groups.
- Five (5) stakeholders working on site with families: URCO research assistants, professionals who participated in the annual event, stakeholders from the working groups where patient-resources are involved, participants in the MUSCO workshops on the integration of patient-resources, members of the plenary committee and an IEN.

These elements were also measured in individual interviews with external partners.

EVALUATION OBJECTIVE 3

- **Measuring the transformations induced in the professionals' practices.**

Does MUSCO contribute to the improvement of practices focused on patients' needs?

Methodology :

One (1) focus group of four (4) professionals in contact with families: physicians involved in different projects, professionals who have participated in the annual event and a practitioner who has contributed to teaching tools and activities (e.g. Bootcamp and manual in pediatric surgery).

2.2 COLLABORATION COMPONENT

EVALUATION OBJECTIVE 4

- **Measuring the transformation of ways of working together and the effects on their practice: climate of collaboration, creation of bonds, effects on practices.**
- **Measuring the perception they have of relationships with other external partners.**
- **Identifying the drivers and barriers to collaboration as well as possible solutions.**

What is the quality of inter-institutional and interdisciplinary interactions and the quality of interactions with external partners?

Does MUSCO enable a positive transformation of inter-institutional collaboration?

What lessons can be learned from the MUSCO collaboration model?

Methodology :

Two (2) focus groups:

- One (1) group of five (5) individuals involved in MUSCO committees or working groups.
- One (1) group of four (4) members of the MUSCO team: an IEN, the genetic counselor, the manager and the project and communications manager.

An online questionnaire was sent to the participants of the first group in order to clarify certain elements, refine and position certain opinions.

Seven (7) individual interviews with the hospital administrators, hospital foundations and the Mirella and Lino Saputo Foundation to explore relationships with other partners, drives and barriers to collaboration.

EVALUATION OBJECTIVE 5

- **Measuring the participation of external actors in the Initiative and the impact on practices.**
- **Measuring and qualifying the interactions and collaborations of community organizations with the four (4) institutions.**

Does MUSCO strengthen the quality of collaboration with external partners?

Is the quality of collaboration with families within MUSCO recognized?

Methodology :

Ten (10) telephone interviews with the different actors of the working groups and organizations that work with the Marie Enfant Rehabilitation Centre or that participated in the annual event.

EVALUATION OBJECTIVE 6

- **Measure the reproducibility of the model for other clienteles: signature of agreements, implementation of actions**

What lessons can be learned from the MUSCO collaborative model?

Methodology :

One (1) focus group with four (4) MUSCO team members (see Objective 4).

3. SUMMARY OF DATA COLLECTION

The various focus groups and interviews allowed us to collect responses to our questions from forty-nine (49) people from June to September 2021 online. The list of participants was approved by the Evaluation Committee. The question grids for each component are available in Appendix II.

In reading this chapter, it is important to consider that the forty-nine (49) individuals interviewed do not represent all projects. The results therefore reflect the position of some collaborators on certain specific projects. Thus, the elements collected should be read as examples of progress, drivers or barriers, and not as exhaustive lists.

Regarding the results on the impact on families, our sample is very small. We can see that MUSCO is not directly linked to families. Rather, the projects have an impact on the services, and therefore indirectly on the families. Consequently, it is difficult to reach families who are sufficiently familiar with MUSCO and its scope, as well as the potential effects of the projects on their lives.

The results obtained do not allow us to affirm that MUSCO directly improves the quality of life of families. However, the few families we met felt supported, and several workers in direct contact with patients perceived an improvement in this regard.

Finally, concerning collaboration between institutions and with external partners, the sample of people we met was diverse enough to have a reasonably accurate idea of the progress and drawbacks. In fact, we spoke with members of the administration, managers, physicians, staff working on-site and external partners who had participated in various projects.

3.1 IMPACT ON PATIENTS/FAMILIES

3.1.1 Evaluation Objective 1 : the quality of support provided to/received from families

Main Developments

Families are increasingly at the center of discussions when it comes to consulting or informing them. Also, facilitators such as the ITA or the genetic counsellor bring considerable added value to the smooth running of their trajectory:

- Families are increasingly at the center of discussions when it comes to consulting or informing them. Also, facilitators such as the IEN or the genetic counsellor bring considerable added value to the smooth running of their trajectory:
- Families seem to feel better heard, understood, informed. This improvement was made possible by the creation of spaces and resources that allowed parents to be listened to and considered.

- Families seem to have a better understanding of the hospital system in which they are navigating and are thus better able to orient themselves and make informed decisions based on their knowledge of the mechanisms in place.
- The impact of the Inter-establishment Navigator (IEN) position on families and on interventions as a referent is considered a major advance by both families and caregivers. She offers families the opportunity to have a more global and simplified view of all their follow-ups, to better understand the planned meetings and thus to take control of their pathway. Also, her ability to direct families to the right resources facilitates and reassures each family in their experience. The IEN provides a link with new practitioners and plays an awareness-raising role with practitioners from one institution to another. By compensating for service disruptions, it also raises questions and suggestions that the teams do not specifically identify. She represents a pivotal resource for promoting collaboration between institutions and workers.

"She's like a super facilitator who knows the tricks of the different institutions."

"She occupies a gatekeeper role for the parents."

"We help them find the 'little doors' that exist between institutions."

- The genetic counselor also represents a significant progress simply by being present and through her effective support (quick answers, ease of contact, very good response to the questions asked, regular contacts, good popularization of the information...).

Drivers

- Concerning the Quality of Life Questionnaire (AMIKO) project, the administrative follow-up through new IT practices is appreciated by all stakeholders (ease of making appointments, online questionnaires, CENTRO system, transmission of information and requests possible by email, which saves many trips).

Barriers/Challenges

- Some families, as well as several stakeholders, do not perceive an overall improvement in patient-centered practices. Apart from the IEN, families do not feel supported in their journey by other stakeholders. There is a possible lack of collaborative channels between families and a variety of stakeholders so that their needs are better considered.

"The needs of the families are not yet at the heart of the intervention of the institutions, because they are overwhelmed and caught up in all the processes. It's rare that we really stop in a follow-up to validate with the family what they want, what they need."

"Changes in practice absolutely need to be supported, taught, understood and loved over the long term."

"At Children's Hospital, we are not familiar with the IEN or the questionnaire.... Collaborations should be set up."

- There is also an issue of access to patient clinical data between establishments, which can complicate the tracking of records.

3.1.2 Evaluation Objective 2 : the quality of collaboration between families and professionals

Main Developments

There is a growing awareness among families of the hospital system and its many mechanisms. This awareness and the new place that patients can occupy in their care trajectory maintains a better quality of experience for families:

- There is a better understanding of how the hospitals work on the family side. Through the Initiative, parents learn about services they were not aware of before. Parents are more engaged in the care journey.
- Families also become aware of other support opportunities (e.g., disability grants, student counseling, etc.) that can support their child's journey.
- Families feel that they are listened to by the professionals who consult them on various occasions and that their comments are taken into account within the Initiative (e.g., comments taken into account during the event on skeletal dysplasia).
- Families are primarily represented through the Care Coordinators and the IEN, who bring the care experience back into the discussion spaces. Processes have already been changed as a result of the advice shared by the IEN.

Drivers

- For the Skeletal Dysplasia event, two subcommittees were created: a Social Committee and a Medical Committee.
- The MUSCO coordination team is an important support, acting as a messenger between the committees and subcommittees.

- Teleconferences facilitate attendance and time management.
- The online questionnaires (AMIKO) are important facilitators: people trust this system, which is appreciated because it facilitates follow-ups.
- The evening and weekend meetings are greatly appreciated by the families.
- It is important to involve parents in projects that concern them directly so that they feel interested and have the motivation to get involved.
- The MUSCO Initiative's principle of neutrality is greatly appreciated, as it allows for a certain amount of freedom of expression in the processes.

Barriers

- It is difficult for parents to make time for the consultation spaces because they are so busy caring for their children.
- According to several professionals, there is a need to change the culture of welcoming parents by giving them more space for reflection in the Initiative's projects. Stakeholders are more or less aware of the importance of family participation. Sometimes committees do not know how to consult and consider families' opinions.
- The importance of educating and training stakeholders to spend time with families to learn about their opinions and experiences was also highlighted.
- There is a need to continue to improve processes to give families more space.

3.1.3 Evaluation Objective 3 : the transformations induced in professional practices

The only projects discussed in this section are DNA sequencing, the genetic counselor, the Quality of Life Questionnaire (AMIKO), as well as the surgical training (Chair). The various comments shared below were collected from a limited sample of participants.

Main Developments

The provision of new resources and tools leads to better monitoring of patients and their needs:

- Thanks to the MUSCO genetic counselor, it is now easier to offer genetic diagnoses that could not be offered before. Families have direct access to a clinical diagnosis.
- The genetic counselor allows for the professionalization of the support work.
- As part of the Quality of Life Questionnaire (AMIKO) project, a great deal of work has been done to date on computerizing the questionnaires, which represents a major step forward in the transformation of practices.

- The genetic equipment acquired as part of the DNA Sequencing project makes it possible to make diagnoses that were not possible before. This improves the detection of problems, as well as the monitoring of their evolution.
- As for the tool for the online Quality of Life Questionnaires, it is not fully developed, but it will certainly improve access to information that will allow for a better understanding of patients' needs.
- The bootcamp and fellowship in pediatric surgery on the unique patient approach are improving specific pediatric practices and medical providers' interactions with families.

Drivers

- Computerization of the questionnaire facilitates the patient experience and improves management through easy access to data.

Barriers

- There is still a lot of computerization work to be done for the questionnaires. Eventually, this will greatly facilitate the process for families.

3.2 IMPACT ON COLLABORATIONS

3.2.1 Evaluation Objective 4 : collaborations between the four (4) institutions involved in the Initiative

Main Developments

We observe that the ways of working together are beginning to change. It is mainly the climate of collaboration and the creation of bonds between the actors of the different institutions that is improving:

- The participants are unanimous in emphasizing that bonds of trust are formed over time.
- Little by little, a friendly climate of openness, respect and interest in the other is being established.
- Many of the actors involved are beginning to understand the Initiative and the relevance of their participation.
- We observe a certain curiosity about others, a desire to link care and procedures (for example, between similar positions in different institutions).
- Some linkages between facilities are beginning to be made.

- Multiple interactions lead to a better knowledge of people and a better understanding of positions, roles and the system.

The collaborations set up by MUSCO have already had some positive effects on collaborators' practices:

- In general, there is a strong desire to change the way things are done.
- The sharing of practices and expertise is now established.
- The players have the impression that we are now more focused on patients/families than on the achievements of the institutions.

Concerning relations with external partners, the changes are not major. However, MUSCO has allowed the creation of some new relationships for some.

"As we moved forward, the collaborative component became more and more important. The collaborations were, at first, unnatural. We had to provoke collaboration, which led to the creation of a joint position: genetic counselor (which is very helpful and allows us to move forward much faster)."

"It's very easy for professionals, and therefore for families, to know who the people are, what their names are and what their function is. It makes communication flow more smoothly."

"Over time, we now feel in the discussions, that we talk more about the patients and their experiences than about the achievements or practices of this or that institution."

Drivers of Collaboration

- The great importance of the MUSCO team is emphasized by all the people we met. It plays a major role as an intermediary between the various institutions, particularly because of its neutrality and its good knowledge of the system and its actors. Its members are also good facilitators of relationships and of the implementation of committees and projects, so the follow-ups and feedback are effective and useful. Their positive leadership and ability to connect the interests of different stakeholders while keeping the patient and family at the heart of decisions is also noted.
- Creating a space for everyone to express themselves is a frequently mentioned facilitator.
- Recognition of the importance of having different perspectives was also mentioned.
- The presence of management is very important, however it would be necessary to give more space to discussions to challenge projects and question actions.

- MUSCO's neutrality and a clear understanding of the Initiative facilitate data sharing (it was noted that this is easier in clinical than in research).
- The very important roles of the IEN and Genetic Counselor position in data sharing, as well as in the concrete application of collaborative practices, are noted.
- Common issues, projects and interests foster the commitment of the collaborators.
- The fact that concrete and promising projects emerge is very mobilizing.
- The good follow-up of projects in the Full Committee facilitates the collective steering of the Initiative.
- The support of managers for the Initiative, and thus having "permission" to work with the right people, is necessary.
- For some, funding has sparked collaborations, broken down silos.
- Working virtually is an asset for some people we met.

"The greatest facilitator of collaboration is the presence of the MUSCO coordination team, which acts as a liaison between everyone, facilitating contacts and meetings. Their presence is really valuable."

Barriers to Collaboration

Some elements of the current organizational cultures in the four (4) institutions and in the hospital environment in general are a constraint to collaborations:

- Differences in organizational cultures hinder collaboration: different interests, functioning, resources.
- Traditional management methods (top down/bottom up) are not conducive to a smooth operation between collaborators.
- The slowness of the environment, the delays in resolving problems are demotivating.
- MUSCO seems to be a very closed initiative with respect to its ecosystem and the hospitals are quite closed in on themselves. The partnership, even with four (4), already seems complex.

"We're starting far down the road in terms of collaboration, I don't think buying a machine will particularly help it." - (COMMENT MENTIONED IN CONNECTION WITH EQUIPMENT ACQUISITION IN ONE OF THE PROJECTS)

The history between the institutions and the reciprocal relationships also sometimes have a negative impact on the collaborations:

- A history of interpersonal relationships sometimes makes it difficult to interact.
- Some people do not return calls, do not answer messages.

Many collaborators doubt that the right people are targeted to sit on the right bodies, according to their skills rather than their status:

- It is important to identify the right people and what they can bring to the projects.
- There is an issue of equity between the four (4) institutions: sometimes there is a search for equality instead of focusing on the right people and the right expertise.
- There was no representative from Children's Hospital on the Bureau of the Initiative, even though these discussions must be done with four (4) institutions.
- The presence of foundations was seen as a barrier to collaboration by some because of the protection of funds, which is important.

The question of time plays a major role in the establishment of fruitful and structuring collaborations:

- Staff lack the time to participate in meetings.
- Several people feel that there are too many meetings, too frequent and too long, and that there is a lack of efficiency.
- The committee structure is often questioned, and some people feel that it is too heavy for the funding provided.

"People go because it's expected of them by donors."

The decision-making processes seem to be too heavy, and there is a need to be more efficient in order to keep managers involved.

The mechanisms around funding were also challenged by some participants:

- How the funding was initially allocated, over what period of time, etc. was identified as a barrier by some collaborators.
- Some people questioned the fact that an amount of money was given before an objective was identified.
- For some, money hinders collaboration by creating competition.

There is a sense of competition between institutions, as opposed to true collaboration:

- For many, there are still a lot of barriers between institutions, a lot of work to be done to break them down.
- Some people talk about a certain level of competition between institutions.
- Some emphasized that the hospital world is an environment where there are many egos.

Regulations, procedures and bureaucracy are major obstacles to collaboration:

- The regulatory aspect, laws and regulations complicate things.
- We often encounter a complexity in the sharing of resources (e.g.: questioning by the Collège des médecins regarding kinesiology practices).
- Several collaborators encounter many obstacles to data sharing: ethics, research standards, administration.
- The Quebec law limits access to certain information (e.g. medical archives).

Lack of awareness of the Initiative, its complexity, and lack of information about its results also slow down the establishment of collaborations:

- Some projects are not sufficiently publicized or known.
- For many, there is a lack of knowledge about MUSCO, its objectives, its projects and their scope.
- We do not see the results or the evolution of the progress of the Initiative or the projects.
- There are many projects, it is difficult to have an overall view.

A few people also identify that the choice of high-impact projects or the scope of the Initiative results in efforts being focused in certain places only, which can slow down the involvement of some collaborators.

"For the Shriners, which is more specialized, there is a big impact in the institution, for the others, we're talking about a very small number of patients involved, people have to get involved for just a few patients."

The pandemic context has certainly hindered the development of new collaborations in some areas:

- Virtual meetings are not conducive to bonding.
- The pandemic has slowed down some of the projects.

3.2.2 Evaluation Objective 5 : collaborations with external actors

Main Developments From the External Partners' Standpoint

Stakeholders outside the Initiative value their participation in the projects:

- Participation is good, partners are motivated to be part of this Initiative.
- The collaborative climate is evolving. We feel that we are moving towards more trust, openness, curiosity, sharing of experience and expertise.

- The collaborations are fluid, we feel more like stakeholders than external collaborators.

There is little impact on practices per se, but rather on relationships:

- The effects observed are essentially in the area of networking.
- We can see an evolution in mentalities, a promising change in culture.
- We are getting to know each other better, and therefore we are better able to advise, accompany and refer families.
- There is no real creation of new relationships, but rather some opportunities for collaboration, for new conversations.
- We generate and share learning at times.

"It also created new conversations, like talking about early childhood and inclusion in daycare for toddlers with disabilities."

Appreciation of the interactions and collaborations between the community organizations and the four (4) institutions is highlighted:

- We link different worlds: institutional, hospital, community, early childhood, school, family...
- We hear the needs of families through organizations, which are sometimes more accessible than the medical world.

Drivers of Collaboration From the External Partners' Standpoint

- The type of leadership of the people who carry and facilitate collaborative projects is a major asset. They facilitate adherence to the vision, ensure that all stakeholders are considered in decisions, inspire trust, play a pivotal role with external organizations, facilitate meetings, and conduct follow-ups and reminders.
- The position of the IENs is also important, ensuring follow-up between the collective work of the committee and the concrete actions taken on-site (a point of vigilance: everything seems to rest on the shoulders of a single person).
- The importance of networking and getting to know each other better as individuals, the roles and responsibilities of similar functions in other institutions, and having a link with key people was also repeatedly stressed.
- Some participants also report collaborative values, attitude and behaviour congruent with these values as notable facilitators. These include respect, consideration and recognition of patient expertise.
- The Executive Committee facilitates external collaborations, by including different stakeholders and providing a clear direction and

message that they are four (4) equal and committed partners. This also gives legitimacy to the projects.

- It is also important to be able to take/allow time for these moments of discussion, to provoke them in official and recognized moments.
- Certain work methods also encourage collaboration from the point of view of external partners: remote meetings, collaborative tools, established sharing methods. But there is still work to be done on this aspect of research and its requirements.

"When you know each other, you know who to talk to, you understand the system, you have more confidence, it makes conversations and even projects easier."

Barriers to Collaboration From the External Partners' Standpoint

The difficulty of publicizing this large-scale Initiative hinders collaborations for external partners:

- The size and complexity of the Initiative is an issue: updating in small working groups, difficulty in follow-up, lack of a common vision of the whole.
- Communications (website...) should be improved. There is a sense of working in isolation. There is a lack of knowledge about the Initiative, who is involved and how, which projects are supported.
- There is a lack of transmission of information and visibility, functioning in closed silos.

Certain research practices also tend to impede the development of collaborations:

- Display and dissemination of research results: it is difficult to have access to data, there is a need for transparency and to proceed gradually.
- Changes in research practices: working on qualitative research with protocols established for quantitative research.

The reality and operation of institutions in terms of administration, procedures, and collaborative practices are also an issue:

- The complexity, rigidity and heaviness of procedures, protocols, paperwork, sometimes of the people themselves (rules, ethics committee, approval process).
- Differences in operations, rules from one institution to another, administrative realities between different networks.
- Difficulty in connecting with physicians, lack of communication with them and between them.
- Distrust between institutions, issues of attracting clients and patient volume.

- The "political" aspect of the Initiative and the tensions that this generates: we prevent ourselves from saying things, we take a lot of time to word things so as not to offend, so that "it will be acceptable".
- The formality of the meetings, practices that are more passive than participative.
- The lack of time of the stakeholders.
- The lack of human resources and the high turnover: fewer professionals, less time, less knowledge of the issues, less knowledge of the network...

For some, not being fully integrated into the MUSCO Initiative is a barrier to collaboration. Indeed, it implies that one is not involved in the upstream reflection of projects, or that one is not part of certain projects, even though this involvement would have an effect on patients/families.

We also note the lack of knowledge of existing services and resources, especially in early childhood, when children do not yet have a precise diagnosis.

Finally, for many, COVID slowed down all the projects and the collaborative process: the "distance", the lack of informal networking time and the creation of bonds of trust, the decrease in visibility for MUSCO.

"We must be vigilant to keep the well-being of patients and families at the heart of everything, never forgetting to take care of the bonds they create with an institution, a doctor. Families must not feel abandoned or sense a breach of service, they must be prepared, informed, reassured, given explanations."

3.2.3 Evaluation Objective 6 : reproducing the model for other clientele

Main Developments Towards Replicating the Model for Other Clienteles

In general, there is a strong interest among the people we met to develop the MUSCO Initiative model in other services, for other clientele. The collaborators and external partners see MUSCO as a pilot project to be extended to other clientele.

In terms of sharing the tools generated by the MUSCO Initiative projects, the Guide on the integration of resource patients was shared with other actors, outside the Initiative's partners and collaborators.

It is interesting to note the existence of models similar to MUSCO: in Toronto with the SickKids Initiative, or in New Brunswick in an intersectoral model involving the entire life trajectory of the child.

Success Factors for This Type of Initiative

The first success criteria is the role of the team that supports the Initiative:

- The perseverance of the Initiative's leaders is a major ingredient.

- The presence of the MUSCO coordination team allows them to absorb the difficulties, to work " behind the scenes ", to facilitate the life of the actors and slowly to find solutions to overcome the obstacles.

The role and attitude of the partners are also essential:

- We note the role of the "champions" who believe in it, who carry it, who spread it.
- The patience of everyone is also very important (donors, management, teams). You have to accept that it will take time.
- You have to really consider the support of the culture change, and not only target the result.
- You have to take the time to develop bonds of trust between the decision-makers.
- Being open to the Initiative and listening to what people are experiencing are also elements that promote success.

The goal, the impact for all, must remain central to discussions and decisions:

- It is important to stick to the ultimate vision, not to deviate from the goal and the collaborative approach.
- We also talk about a "win-win" initiative: it is not only MUSCO that benefits from the Initiative, there is also a sharing that enriches each of the actors.

Finally, evaluating oneself, identifying good moves and challenges and learning from them are undeniable conditions for success.

Barriers

With MUSCO, the initial idea is to demonstrate, for a given clientele, the impacts of better collaborations and to document them in order to be able to ask the Ministry of Health for support in transforming the trajectories of all clienteles.

The current level of collaboration and its actual impacts do not seem entirely clear. More time is needed to test and transform collaborative practices. However, participants believe that some promising solutions could be applied to other clienteles.

However, it is still difficult to integrate all the ideas and developments at all levels.

3.3 MAIN CHALLENGES IDENTIFIED

Following the analysis of all the information collected, we are able to establish thirteen (13) major challenges that are organized into five (5) themes.

Concerning the position of families in the Initiative :

Challenge 1: The representativeness in terms of number and diversity of families both within the bodies and in the discussion mechanisms must be improved to optimize the understanding of needs and provide adequate solutions.

Challenge 2: The work related to facilitating the trajectory must be continued to ensure a truly effective change in the lives of families.

Regarding projects:

Challenge 3: The needs of families must be known, considered and prioritized in the choice of projects and decisions made within the Initiative.

Challenge 4: Communication must be further improved to facilitate the appropriation of a complex and consequent initiative with the intention of engaging and involving the stakeholders.

Challenge 5: Follow-up on projects and results should be more widely reported in order to develop skills and share learning.

Challenge 6: Major transformations in professional practices are needed in order to generate a concrete impact in the trajectory of families.

Concerning the collective management of the Initiative:

Challenge 7: It is necessary to rethink the optimization of governance and the contribution of each person in order to maintain the mobilization and commitment of the different actors (which bodies, which roles, who sits where, positioning of the different actors).

Challenge 8: In order to have an impact on the child's entire life trajectory, it will be necessary to open the Initiative more broadly to other sectors (community, school, etc.).

Concerning the organizational culture of the four (4) institutions:

Challenge 9: Procedures, regulations, administrative constraints, and major differences in operation from one institution to another hinder collaboration between the institutions on the one hand and between the institutions and external partners on the other.

Challenge 10: The management of cultural change is necessary with respect to the culture of collaboration, poor communication, the medical-centric perspective, the place of the different professions and their mutual consideration.

Challenge 11: The dynamics of cooperation from an institutional and expertise standpoint, as opposed to competition and mistrust, still need to be worked on (moving from discussion to collaboration, giving each other space to challenge and influence practices and strategies).

Concerning the funding of the Initiative and the projects :

Challenge 12: Current funding allocation and accountability mechanisms are detrimental to the collective process (allocation of money per institution without regard to objectives, accountability per project...).

Challenge 13: The sustainability of the Initiative is important in order to maintain promising innovations, gains, and even model MUSCO.

4. COLLABORATOR RECOMMENDATIONS

A total of twenty-three (23) internal collaborators and external partners participated in two (2) workshops to submit recommendations and practical proposals to move the Initiative towards a greater impact on the quality of life of children with musculoskeletal disorders and their families. It is important to note the variety of participants: Patient Experts, members of the working groups, institutional directors, foundation representatives and external partners.

Seven (7) issues identified by the members of the Evaluation Committee as being the most structuring were addressed during the workshops. For these seven (7) issues, the workshop participants were able to explore possible solutions and recommendations.

The following paragraphs present all of the recommendations and practical proposals, including the recommendations made during the focus groups and individual interviews.

Challenge 1: The representativeness in terms of number and diversity of families both within the bodies and in the discussion mechanisms must be improved to optimize the understanding of needs and provide adequate solutions.

Avenues to explore and recommendations:

Increase and improve the inclusion of parents and make efforts to accommodate them:

- Suggest pairing up parents.
- Invite more than one parent per working group to balance representation.
- Solicit parents who have experience and who know the network well and encourage them to be ambassadors and to support "new" parents.
- Be more creative to encourage parent involvement. Example: go to where parents are already, express themselves and use this data.
- Also improve communication with parents: share what MUSCO does and for what purpose, facilitate understanding with concrete testimonials from parents (how they can collaborate, get involved).

- Give feedback from other projects to parents, to give a global idea of the evolution of MUSCO.

Challenge 2: The work related to facilitating the trajectory must be continued to ensure a truly effective change in the lives of families.

Avenues to explore and recommendations:

Continue to build on the human resources that facilitate the trajectory:

- Create several IEN positions (note that a second IEN has since been hired).
- Clarify the IEN role (as well as the role of the pivot personnel) with families and center partners and who can access them.
- Create several genetic counselor positions to increase the number of diagnoses possible.

Improve communication mechanisms:

- Know who to call, when to call, and the names of professionals that families can contact directly.
- Clarify processes and mechanisms to better communicate them to families.
- Have reference documents for "routine" procedures so that parents have access to key information.
- Develop a common database for all facilities to facilitate tracking of user data. Create an inter-institutional communication and information portal, similar to the Dossier Santé Québec (DSQ), which brings together files/documents/files from each institution that are not usually found on the DSQ.
- Ensure that physicians have access to their records in all centers. Ensure that remote access is used and validate whether non-physicians can obtain this access.
- Improve collaboration and communication between centers and stakeholders regarding patient records (e.g., medical records). Develop an information exchange protocol or contract between the CHU Sainte-Justine and the Shriners
- Develop better responsiveness (access to information, responses to emails).

Implement tools to support the parent:

- Clarify, from the beginning of the family's journey, the inter-institutional links and develop a tool for the parent to follow his or her own trajectory (medical and/or administrative information).
- Ensure that the parent can reach someone with questions and that they will get a response within a reasonable time (or at least an acknowledgement that their request is being addressed).

- Create a passport between facilities for tracking medical appointments (mobile app or other).

Improve communications with partners:

- Involve partners from the rehabilitation and social community networks (e.g., the Lethbridge-Layton-Mackay Rehabilitation Centre of CIUSSS Centre-Ouest).
- To make available the list of names of the key workers in the partner centers.
- To update the Act respecting health services and social services regarding the means of information exchange.

Work on the posture of professionals:

- Develop a greater ability to listen to parents who are at the forefront of the child's life and demonstrate an openness to learning more about the child's reality, so that families can be better guided to the right professionals who will need to take over.
- Accept that each child may need a different trajectory (even if, on paper, they have the same diagnosis as "their neighbor") and that parents have many questions.
- Demonstrate an openness to communicate with other professionals who are more familiar with the child's case.
- Be aware of the professionals already in the file and communicate with them, if required.
- Do not rely solely on the child's medical record; also rely on the clinical examination (e.g., how the child is doing).
- Identify a "multi-center" pediatrician to follow patients (and their complex medical conditions) during surgical episodes.
- Obtain feedback from parents when they no longer need trajectory services (transition to adulthood, death, care elsewhere, etc.) and take action accordingly.

Challenge 3: The needs of families must be known, considered and prioritized in the choice of projects and decisions made within the Initiative.

Avenues to explore and recommendations:

- Create several IEN positions to facilitate the transfer of information and awareness among the various stakeholders.
- Develop new consultation spaces to better identify the needs of families.
- Consult with a variety of families involved in these care trajectories to ensure a better representation of needs.

- Educate and train caregivers to take the time and insist on the presence and voice of parents.

Challenge 4: Communication must be further improved to facilitate the appropriation of a complex and consequent initiative with the intention of engaging and involving the stakeholders.

Avenues to explore and recommendations:

Improve and support the dynamics of collaboration:

- Be able to communicate the real issues at stake, whether they are institutional or relational...
- To identify and enforce the values of the Initiative by all partners.
- To give missions to the different teams, who have to report the impact of their projects in order to adapt the follow-up and to share information.
- Question the place of the MUSCO coordination team in the ecosystem and the value of giving more responsibility to the working groups to engage them more in the steering of the Initiative.
- Invite collaborators to get involved in the committees: ask people to get more actively involved (call on everyone to create the working groups).
- Target people who are interested.

Communicating the Impact of the Initiative:

- Raise awareness of the needs of families and patients, to which MUSCO contributes.

Create and deploy communication tools:

- Write "success stories" about the journey of some families.
- Create an " ambassador squad " to present the Initiative to different targeted channels.
- Set up an annual conference to present progress (patient testimonials, project presentations) rather than an annual report.
- Establish better visibility on all resources. Example: directory of clinical research collaborators.
- Reduce the length of newsletters and propose video capsules instead.
- Work on a more dynamic communication medium (testimonials, spotlighting certain people, etc.).

Challenge 5: Follow-up on projects and results should be more widely reported in order to develop skills and share learning.

Avenues to explore and recommendations:

Ensure a clear understanding of the Initiative, its importance and intended impacts:

- Guarantee more sharing between the different working groups, allow them to better understand all the projects.
- Facilitate cross-fertilization, a more global vision, more sharing of cross-cutting practices.
- Monitor projects. For example, the guide: what is being applied in practice? What are, in the end, the most promising recommendations?
- Raise awareness among professionals to engage in workshops to give them the tools to know how to get involved, how to develop projects, how to interact with families in project mode.
- Learn to know the needs of families, listen to them, conduct studies or discussion groups to bring out the needs of families and feed the practices of professionals.
- Harmonize practices within the same team, within the same institution and between institutions.
- Get senior managers to spend time with their teams in the field to build mutual trust, so they can see the challenges and successes and escalate solutions to decision makers.
- To change practices in a sustainable way, take into account the fact that we work in an interdisciplinary environment: we need to make things more accessible, to adopt a common language, to explain the issues and to allow for the same level of understanding in order to build effective exchanges. Create a place, a place of exchange so that the elements are understandable for all.
- Create peer committees, multidisciplinary councils (bring together the various professionals): allow for meeting spaces, support for interdisciplinary services for the development and sharing of skills.
- Be aware of the complementarities of service offerings and skills in order to truly engage in co-design upstream or at least, from the beginning of a project, identify the priorities for the year (e.g., "lunch and learn" to present what everyone is doing).
- Allow time to have opportunities to discuss, create moments, without necessarily being official events, simply privileged moments.

Establish and deploy monitoring and reporting mechanisms:

- Hold an annual conference to present the previous year's successes, with testimonials from participants and beneficiary families.
- Increase the visibility of progress on the MUSCO website.
- Organize an "AGM" type meeting with all stakeholders, open to organizations and individuals interested in learning more even if they are not collaborators.
- Participate in conferences of other organizations to present the Initiative and its results.
- Participate in specific events at individual institutions.
- Offer presentations about the projects at events by different presenters.

- Share project progress, experience, and success stories among collaborative project managers to move forward more efficiently and to avoid the "12 labors of Asterix" for each team.
- Create simple and powerful capsules or PowerPoints to be displayed on institutional screens to promote success stories (in "Did you know that?" mode)

Challenge 6: Major transformations in professional practices are needed in order to generate a concrete impact in the trajectory of families.

Avenues to explore and recommendations:

- Extend the Initiative to more stakeholders to achieve a more comprehensive effect.
- Plan projects by taking into account stakeholders and different actors earlier in the development of projects and decisions. For example, in the case of AMIKO, include physicians earlier in the process to benefit from their expertise, opinions and ideas...
- Keep an open mind, in each institution, about what is being done elsewhere in Canada to improve practices.
- Create a Montreal center that goes beyond the individuality of each institution, a common place that is inclusive and open to innovation.

Challenge 7: It is necessary to rethink the optimization of governance and the contribution of each person in order to maintain the mobilization and commitment of the different actors (which bodies, which roles, who sits where, positioning of the different actors).

Avenues to explore and recommendations:

Optimize the moderation of committee or working group meetings:

- Change meeting habits: develop collaborative habits versus passivity of participants in meetings.
- Generate more natural interactions online, adjust methods and tools to the context of videoconference meetings.
- Organize brainstorming groups, give tasks, allow space for challenging each other and then come back to the donor and report on progress.
- Involve frontline staff in meetings to present progress.

Improve governance and decision-making processes:

- Improve approval processes: they are currently too long and complex. Bring fluidity to the steering of the Initiative.
- Develop a tool to help choose how to meet with the core group: face-to-face or online meetings, modes of communication, etc.

- Rethink who is involved, where and when, make sure to choose the right people at the right time.
- The Advisory Pole: what will be its concrete role in reality? Where are we with this project? What does it achieve?
- Concerning the bodies :
 - Full Committee: think of a new formula, focus on four (4) or five (5) projects by inviting stakeholders involved in the projects, ask for testimonials.
 - Ask for the Full Committee's input to promote the Initiative: share progress, realignments, highlight patient/family collaboration.
 - Steering Committee: to be dismantled (institutional leadership now sits on the Executive Committee)
 - Executive Committee: do not make changes, but include new people from the Steering Committee.

Reflect on the roles and positions of everyone:

- Ensure more accountability from institutional management in the delivery of results.
- Allow staff to be involved at different levels (on projects or in governance).
- Think about the donor's position: when they speak their mind, the stakeholders follow - the speech is not necessarily always free.

Challenge 8: In order to have an impact on the child's entire life trajectory, it will be necessary to open the Initiative more broadly to other sectors (community, school, etc.).

Avenues to explore and recommendations:

Focus on certain players:

- Need to involve all levels of management to implement systemic change.
- Find ways to involve more physicians in the thought process.
- Support the role of IENs: they are an important agent of change.

Expand the stakeholders included in the MUSCO Initiative:

- Work as transversally as possible, break out of our silos.
- Include more external partners in identifying priorities and how to work together: real partnerships.
- Include other organizations that could be beneficial to the MUSCO Initiative, such as the MacKay Rehabilitation Centre and the community sector (e.g., groups, regional structures, etc.)
- Better inform external partners, include them more (e.g., calls for collaboration).

Develop meaningful partnerships:

- Better understand each other's roles and existing expertise (e.g., inclusive practices in early childhood) and deploy them.
- Optimize access to services and equipment (e.g., rehabilitation centers could probably lend rehabilitation equipment to child care centres that really need it).

Point of concern:

We must be vigilant in keeping the well-being of patients and families at the heart of everything, never forgetting to take care of the bonds they create with an institution and a physician. Families must not feel abandoned or feel that the service has been disrupted; they must be prepared, informed, reassured and given explanations.

Consider the child's trajectory more broadly:

- Share a tree of life between the sectors, practitioners should know the resources, create a reference directory to inform parents.
- Conduct an analysis of the needs of families for each diagnosis (projects, regardless of the collaborators involved, must be rooted in the needs of families).
- Ensure that information is transmitted to the right environment, to the right person.
- Ensure that for children aged 0 to 3 years, healthcare workers are aware of the resources available.
- Include representatives from community organizations or other sectors in project working groups (as was done with the Association québécoise des Personnes de Petite Taille for the annual Dysplasia event).
- Create spaces for discussion and brainstorming outside of the projects identified in MUSCO (meetings, discussion groups), on an ad hoc or regular basis (annual forum with presentation of MUSCO results and success stories and spaces for brainstorming and discussion).
- Identify and establish collaborations between the different partners. Obtain a picture of the partner community and their possible involvement in the Initiative.
- Plan for a transition from pediatric to adult care (difficult transition at 18, each facility follows its own transition plan and there is no cohesion between the different centers).
- Explore how clinicians could be more aware of the existence of organizations, their work, possible connections.
- See about exporting trajectory tools developed within MUSCO (e.g. Skeletal Dysplasia Resource Chart).
- Identify how to better work with schools.

Challenge 9: Procedures, regulations, administrative constraints, and major differences in operation from one institution to another hinder collaboration between the institutions on the one hand and between the institutions and external partners on the other.

Avenues to explore and recommendations:

- Work on policies and regulations to make them as responsive as possible to inter-institutional collaborative practices.
- Improve communication between centers regarding patient records (e.g., X-rays, medical records - see to the development of a common database for all institutions).
- Better understand the positions and roles in each institution to facilitate connections.
- Establish formal communication lines and processes that are recognized and supported by management.

Challenge 10: The management of cultural change is necessary with respect to the culture of collaboration, poor communication, the medical-centric perspective, the place of the different professions and their mutual consideration.

Avenues to explore and recommendations:

Involve the various professions in the process:

- Involve all levels of management to implement systemic changes.
- Allow care teams to be stakeholders in the changes.
- Involve everyone in discussions to ensure that everything is in place for success (e.g., from surgery to rehabilitation).
- Respect different specialties, all expertise is important and should be included (e.g., the floor should not be reserved for physicians only).

Involve families in the process:

- Highlight the known benefits of working with families, showing the impact of families' contributions in very concrete ways.
- Create more opportunities to work with families.
- Provide experiences that allow for learning how to work better with families (including how to mobilize the knowledge of different parties).
- Share among centers the respective level of involvement of families. Then identify what could be implemented in a common way.
- Involve families to ensure a good understanding of their needs:
 - Families will be more active in their trajectory if they are engaged.
 - Families will feel that they are contributing to their own care.

Learn to collaborate:

- Offer more training to learn how to collaborate.
- Build on and share successes, such as communications successes.
- Show that "it's not that complicated".
- Demonstrate the impact of inter-institutional collaboration.
- Collect the complementarities and benefits identified by collaborators.
- Share between centers the ways in which each organization collaborates. Then identify what could be implemented in a common way.
- Develop a common definition of what collaboration is and understand the willingness of each stakeholder to collaborate.
- Capitalize on the benefits of collaboration:
 - The better the communication, the more long-term benefits.
 - Smooth collaborations save time for professionals (better access to information, avoid duplication of services).
 - By avoiding duplication of services, more needs of different families can be met.

Establish formal collaborative practices:

- Develop communication ties between the pivots and get to know each other.
- Share expertise between centers in a more formal way, such as through a formal community or communities of practice.
- Ensure that all partners are providing the same information to families, medically, administratively and otherwise.
- Communicate clear information so that the patient knows who to contact.
- Leverage the position of IEN so that each partner works together and feels involved.
- For complex patients, as part of the surgical episode, validate the clinical management by the IEN to ensure that the needs are well addressed.
- Develop follow-up tools to distribute information.
- Cultivate a culture of sharing with formal lines of communication.
- Include the objectives of the MUSCO Initiative in the institutions' strategic plans.

Give ourselves the means at the decision-making level:

- Anchor the culture of collaboration in the institutions, particularly through support from senior management: make the need and intent for collaboration explicit.
- Involve senior management to a greater extent and identify the points of convergence related to the care of the child and to collaboration itself.

- Provide the means to collaborate:
 - Give stakeholders more latitude, more power to act.
 - Structure opportunities to come together to communicate, as projects dictate.

Provide the means to implement organizational culture transformations:

- Collaboration can take time, you have to take the time.
- The desire to collaborate must come from the teams.
- Dedicated time must be given upstream of projects to discuss with all stakeholders, and think about involving the services/stakeholders who will be impacted.
- Make a session plan: define a plan, ask the patient what the needs are and make sure that the initial plan meets the needs.

Focus decisions on the needs of the child and family:

- Identify first our common understanding of what the needs of the child are and work to ensure that collaborations are centered on those needs.
- Have "gatekeepers" of child and family needs on committees and working groups who ensure that they are always considered in committee thinking, discussions and decisions. These gatekeepers should be family/patient partners who understand them better and would be legitimized to say so.
- Involve families in thinking and decision-making. Seek input from families.
- Question families about why they are there, make sure their expectations are met.

Challenge 11: The dynamics of cooperation from an institutional and expertise standpoint, as opposed to competition and mistrust, still need to be worked on (moving from discussion to collaboration, giving each other space to challenge and influence practices and strategies).

Avenues to explore and recommendations:

- Take the time to develop trust between the different collaborators, to get to know each other.
- Keep the well-being of patients at the heart of all decisions and proposals.
- Create spaces for strong interactions to promote inter-influence.
- Work on collaborative practices in depth, learn to work in an intersectoral manner.
- Improve the collaborative dynamic (e.g., responsiveness in emails, follow-up during staff turnover).
- Set up a collaboration office.

Challenge 12: Current funding allocation and accountability mechanisms are detrimental to the collective process (allocation of money per institution without regard to objectives, accountability per project...).

Avenues to explore and recommendations:

- Provide spaces for discussion to really challenge each other in terms of objectives and impacts on patients/families and structuring actions, before allocating funds by institution.
- Propose accountability by inter-institutional project and not only by institution to give a perspective on the scope of the collaborations.

Challenge 13: The sustainability of the Initiative is important in order to maintain promising innovations, gains, and even model MUSCO.

Avenues to explore and recommendations:

Demonstrate the results, the concrete effects of the MUSCO Initiative:

- Demonstrate the importance of what the projects produce.
- Build a case for support after funding ends.
- Showcase results.
- Demonstrate that an ideal trajectory reduces costs.

From the beginning, think of the projects so that the actions can then function without external financing:

- Have projects that can "stand on their own", continue on their own.
- Set up projects so that the transformation is completed within the funding period.
- Focus on equipping current resources rather than creating new needs.
- Make plans to maintain an impact even if sustainability is not possible (e.g., if there are no more IENs, prepare for what comes next).

Sustain the actions and results rather than the Initiative itself:

- Although one can think globally if the donor wishes to continue the project, one must also think in sub-projects.
- We must not think in terms of perpetuating the Initiative, but in terms of projects and outcomes, and these must be directly linked to the objectives of improving the patient-family trajectory.
- Within the large Initiative there are several sub-projects. It should be considered that some of these will continue, to be taken up by the institutional Project Offices.

- It will be difficult to fund the entire Initiative. However, it would be possible to work by stratification. For some projects, various funding could be sought: research funding agencies, government.

Plan the future budget with sustainability in mind:

- Begin by conducting a budget exercise and asking what will be taken over by institutions, what will require external financial support, and what will be dropped.
- Think about the current budget in terms of sustainability.

Prioritize according to actual impacts and potential sustainability of projects:

- Prioritize projects that have a real impact on the patient-family.
- Tailor actions to individual projects. Some projects work better than others. They can be prioritized for possible continuation. In addition, some projects will end. Others can be continued without a large investment, especially if the institutions talk to each other and get along.
- Continue according to the priority of the government and the institutions.
- Be proactive in seeking funding (note: the different teams do not agree on this point):
 - Is it a search for funding to continue MUSCO? Or to pursue certain projects individually?
 - One could deal with a diversification of types of funding depending on the type of project: some will fund the overall Initiative, others per project.
 - On the other hand, it is necessary to think about this upstream and during the project. If sustainability is foreseen from the outset, it no longer requires thought at the end of the project.

Sustaining practices and desired transformations (not just funding):

- Maintain good practices (this does not require money, it is sometimes even a source of savings).
- Leave traces, document, share with other institutions.
- Foresee the question of MUSCO's organizational memory (good practices, lessons learned, processes and procedures).
- Work in transformation, manage the transformation of services.
- Have a sustainability approach from the start, manage for change and not manage a 5-year project.

5. NISKA'S RECOMMENDATIONS

In this section, we would like to draw the attention of MUSCO's collaborators to certain points that we feel deserve a little more consideration than the process has allowed us to give. Our recommendations are therefore complementary to the collective efforts of the participants in the various stages of the process. They are as much about actions to be taken as about reflections to be carried out collectively or practices to be put in place.

Reaching out to families more and better, in a creative way.

Being able to hear the real needs of patients and their families is a fundamental key to improving their journey and their quality of life. It is by properly hearing the needs of patients/families that institutions will be able to put in place projects that will meet them.

However, reaching these families is a challenge. The parents of these children are, like all parents, very busy with their family and professional life in addition to all the care and procedures required by the condition of their child with musculoskeletal disorders and requiring complex care.

We want to emphasize the need to be creative in finding ways to meet these needs by adapting to the realities of parents' lives. For example, as mentioned by the participants, by meeting them in places and at times when they are available or have already been reached on other occasions.

In addition, we feel it is important to take the time to explore with these families how the parents want to contribute, and what really makes a difference in their child's journey from their perspective.

Move towards a holistic vision of the human being.

The challenge that the four (4) institutions in the MUSCO Initiative have taken on is a major one. Ultimately, it is a matter of acting on the culture of the medical sector to bring professionals and all stakeholders to take a more global view of the child with complex health problems and his or her care and life path.

Our conversations with participants during the evaluation process led us to emphasize the importance of changing the posture of health care providers in order to "de-center themselves from the purely medical viewpoint" and thus be able to listen to the transversal needs of families. It is necessary to consider the child in his or her entirety in order to support these families as best as possible in their child's life course and thus improve their quality of life in a concrete and significant way.

Of course, the institutions must remain within the limits of their mission, their role being to provide medical care. However, health can only be global and the consideration of other spheres of children's lives is therefore unavoidable.

This does not mean that pediatric institutions must meet all the needs of these children and their families, but that they must at least be aware of the issues faced by their patients and position themselves with a holistic intent to support and guide them.

Adjust the governance model to serve the project and the patients/families.

As in many collectively managed projects, governance (the way it works, discussions and decision-making) is an issue. We need to think about how it can serve the project and promote collective intelligence, subsidiarity and easier decision-making.

The current operating model is seen as burdensome and lacking in efficiency. Several people feel that there are too many committees, too many meetings, and that these are not used to their full potential (transmission of information rather than in-depth discussions). The composition of committees and working groups was also questioned. In addition, decision-making does not always seem to be in line with the Initiative's objectives.

Finally, in discussions with participants during the evaluation process, it became apparent that current governance appears to be organized around accountability rather than serving the Initiative and its desired changes.

However, the principles of mobilization and collective project management demonstrate the importance of finding a balance between these two necessities, while keeping MUSCO's ultimate goal, which is what mobilizes collaborators, at the heart of everything.

We suggest conducting a thorough review of governance with the various collaborators concerned and involved in order to co-construct a model that is an effective " vehicle " for achieving MUSCO's ultimate goal. The four (4) institutions are on the path to a certain shared leadership by piloting the Initiative together. The next step could be to explore circular models, inspired by sociocracy and subsidiarity principles.

Identify the drivers and adjust the mechanisms that will facilitate collective work.

The first few years of the Initiative have made it possible to establish common working grounds, while at the same time highlighting certain areas that make the quality of cooperation between institutions vulnerable. In order to ensure a smooth transition for families and constructive collaboration between professionals, protocols or initiatives can be put in place to provide appropriate support for families. For example, this may involve establishing reasonable response times to email requests so that families are not kept waiting in their care process. Informal meeting spaces can also be set up so that the various stakeholders can get to know each other better, regardless of their function. These meetings would allow stakeholders to better understand each other's concerns, to better understand each other's roles in the ecosystem, and to create connections that would facilitate both their work and the families' care process. The intention is also to work on the capacity for empathy of the different professions in order to establish a work culture where listening and mutual consideration are present.

Empower stakeholders to identify and implement the changes necessary to achieve the objectives, particularly in terms of collaboration.

Through the various conversations conducted, we note that the interest in collaboration is very present among the " on-site " stakeholders. They are eager to contribute to improving the quality of life of patients/families and firmly believe that better collaborations are an essential

key. However, they do not always have the legitimacy and/or the latitude to make things happen. Moreover, their place in decision-making processes is not always optimal.

We see great potential for MUSCO, especially in terms of making important cultural changes in inter-institutional collaboration. Relying on the people on the front line, those who are in direct contact with patients, who know their needs well and who apply the changes on a daily basis, is necessarily a force for transformation and long-term structuring.

Develop a strategic plan including a financial request for Phase 2 of the Initiative.

While for the first funding of the Initiative, a budget was identified and distributed by the Mirella and Lino Saputo Foundation to the different institutions, our proposal, in the case of an extension of the Initiative, would be that the different organizations involved collectively elaborate a strategic plan for the next few years by associating a financial evaluation to be submitted to the Foundation. The intention is to start from the needs of the community to identify the financial resources to be released in order to achieve the targeted strategic orientations. Also, in order to establish the collective spirit of the Initiative, we suggest that a global financial envelope be granted rather than several financial envelopes assigned to the different institutions.

With regard to the current funding, we suggest that, in light of this mid-term evaluation, the strategic plan be revised to ensure that projects that truly meet the needs of families and achieve the targeted impact are prioritized.

6. PARTICIPANTS' WISHES FOR THE FUTURE OF MUSCO

- Stay focused on the children, on the big goal of improving the lives of these children.
- Review the structure of governance meetings to save people's time.
- Use available resources on high impact projects.
- Give ourselves more time to get to know each other and work better together.
- Learn to work more together.
- Be able to demonstrate real impact.
- Replicate the model in other departments.
- Create sustainability of projects. The next few years should serve to solidify what is planned and implemented.
- Achieve the goals.
- Change the discourse: inclusion is possible!
- Dare to be innovative, MUSCO's own distinction.
- Develop a certain autonomy in terms of facilitating collaborative meetings.
- Linking the different worlds: among others, the hospital environment and community organizations.
- Open the Initiative to more collaborations (in "living lab" mode, for example).
- Make a link with the Ministry's request and the Caregivers Act.
- Make links with the government, seek recognition from the Ministry to bring legitimacy and real support for change in all health institutions.
- Establish ultimate communication between all the Montreal centers. Make everything easier (medical imaging, clinical, research...) and allow for the sharing of expertise.
- Promote the Initiative to several other specialized clinics.
- Be patient: we're talking about a cultural change, it's long! We must give ourselves the time and energy needed to make it work and to be able to demonstrate positive results.
- Continue and enhance inter-institutional collaborations.

CONCLUSION

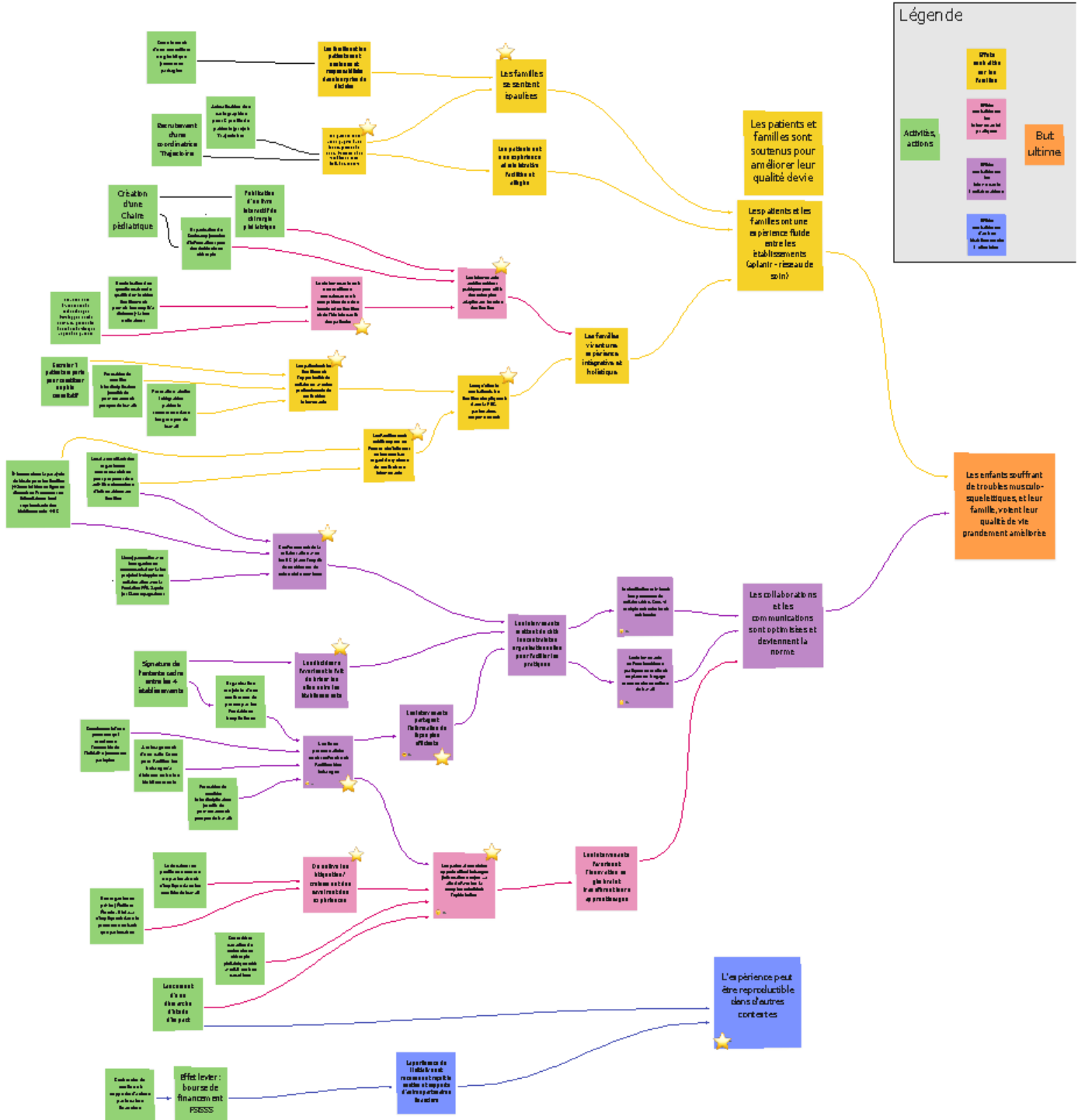
At this stage of the Initiative's implementation, it can be seen that the four (4) institutions are clearly mobilized to make real changes to collectively improve the care and services provided to children with musculoskeletal disorders and complex care needs, as well as their families. We can identify that the foundations for collaboration and mobilization are being put in place, people are getting to know each other, developing trusting relationships, and most importantly, working together around a common patient/family-centered goal.

However, several elements still seem fragile or only in the early stages of transformation. The real impact on families and on professional practices is beginning to be felt, but it is not yet marked. Efforts must be maintained.

Many lessons were learned through this evaluation exercise. The participants in the process also identified several possible solutions for improving the Initiative. These various elements will allow the collaborators to make decisions in order to implement structuring actions that will ensure the achievement of MUSCO's ultimate goals.

In conclusion, we would like to thank all the members of the MUSCO team, all the people who took the time to answer our questions during the group and individual interviews, as well as the collaborators and external partners who participated in the workshops in order to propose recommendations for the continuation of the Initiative and the projects. This report is the result of a collective effort to further improve the journey and quality of life of children with musculoskeletal disorders.

APPENDIX I SIMPLIFIED THEORY OF CHANGE DIAGRAM (available in French only)



APPENDIX II INTERVIEW GRIDS (available in French only)

Questionnaires d'évaluation de l'Initiative MUSCO 2020-2021

A. VOLET FAMILLES

FAMILLES

Objectif d'évaluation 1

Mesurer la qualité du soutien apporté-reçu : familles épaulées, formées, informées.

Méthodologie :

Un (1) groupe de huit (8) parents ou patients maximum – différents publics cibles famille.

Durée des rencontres : 1 h 30 à 2 h.

Détails public cible :

Groupe familles :

- Familles mélangées inscrites dans différents projets.
- Parents et patients participants aux vidéos de l'événement « paralysie cérébrale » et à l'événement comme tel.
- Familles accompagnées par la CTI et la conseillère en génétique.

Indicateurs à évaluer avec les familles :

Est-ce que MUSCO permet d'avoir une meilleure compréhension du besoin des familles menant ainsi à des pratiques améliorées ?

- Perception des patients que leurs besoins sont mieux connus, compris, écoutés.
- Perception de l'amélioration des pratiques centrées sur les besoins du patient.
- Sentiment d'être mieux informé.
- Sentiment d'être mieux formé.
- Sentiment d'être épaulée – Pourquoi ? Comment ?
- Accompagnement reçu – Pourquoi ? Comment ? Bénéfices ?

Déroulement (90 à 120 min)

Accueil

10 min

Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1

5 min

Quel est votre lien avec l'Initiative MUSCO (bénéficiaire, groupes de travail, pôle...) ? De quelle façon y prenez-vous part ?

Question 2

15 min

Avez-vous le sentiment d'être mieux écouté et compris dans vos besoins ? Si oui, comment ? Qu'est-ce que cela a pour effet dans votre parcours ? Explorer les pistes d'amélioration.

Question 3

15 min

Pensez-vous que vous êtes mieux informé, formé tout au long de l'accompagnement ? Si oui, pourquoi, comment ? Explorer les pistes d'amélioration.

Question 4

15 min

Avez-vous le sentiment que vous êtes mieux soutenu tout au long du processus ? Pourquoi et comment ?

Sous-question : Quels effets cet accompagnement ont-ils dans votre vie de parent et auprès de vos enfants ?

Explorer les pistes d'amélioration.

Question 5

15 min

Comment vivez-vous les procédures et les outils administratifs alloués au processus d'accompagnement ? Notamment concernant votre parcours à travers les quatre (4) établissements ?

Avez-vous observé des améliorations ?

Question 6

15 min

Avez-vous observé des améliorations facilitant votre parcours, notamment à travers les quatre (4) établissements ?

Sous-question : Qu'est-ce qui pourrait être fait pour améliorer l'accompagnement qui vous est offert ?

Conclusion et déclusion

10 min

INTERVENANTS

Objectif d'évaluation 1

Mesurer la qualité du soutien apporté-reçu : familles épaulées, formées, informées.

Méthodologie :

Un (1) groupe de huit (8) intervenants terrains impliqués auprès des familles.
Durée des rencontres : 1 h 30 à 2 h.

Détails public cible :

Groupe d'intervenants :

- Prescripteurs accompagnement des familles (services cliniques, TS) - interaction avec la CTI.
- CTI.
- Assistantes de recherche URCO.

Indicateurs à évaluer avec les intervenants :

Est-ce que MUSCO permet de renforcer la qualité du soutien offert aux familles?

- Impact de la coordonnatrice trajectoire interétablissement sur les familles et vos interventions.
- Perception des intervenants quant au soutien accordé aux familles.
- Perception des intervenants qui demandent du soutien pour les familles : Est-ce que ça aide les familles? Est-ce que ça les aide à aider les familles? Comment?

Déroulement (120 min)

Accueil

10 min

Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1

5 min

Quel est votre lien avec l'Initiative MUSCO (groupes de travail, pôle...)? De quelle façon y prenez-vous part? Quel est votre rôle?

Question 2

15 min

De façon générale, quelle est votre perception des effets de l'Initiative MUSCO dans la vie des familles?

Sous-question : Quel genre d'impact la CTI peut avoir sur les familles? Quel impact sa présence a pour effet sur vos interventions?

Question 3**15 min**

Avez-vous observé des améliorations facilitant votre travail auprès des patients depuis l'arrivée de l'Initiative? Si oui, lesquelles et comment?

Sous-question : Quels effets cela a sur votre pratique?

Quel genre d'impact la CTI peut avoir sur les familles? Quel impact sa présence a pour effet sur vos interventions?

Question 4**15 min**

Avez-vous le sentiment de mieux connaître et comprendre les besoins (explicites et/ou implicites) des familles? Quelles transformations cela induit dans vos pratiques?

Sous-questions : Comment se traduisent sur le terrain les besoins partagés par les familles?

Quelles applications concrètes sont mise en place à la suite de l'avis donné par les familles?

Quel genre d'impact la CTI peut avoir sur les familles? Quel impact sa présence a pour effet sur vos interventions?

Question 5**15 min**

Percevez-vous que les familles se sentent mieux épaulées dans leur parcours? Si oui, pourquoi, comment? Qu'est-ce qui facilite ce soutien?

Sous-question : Concernant les démarches administratives allouées, constatez-vous des effets?

Question 6**15 min**

Considérez-vous que la « relation patient-intervenant » a évoluée? Si oui, comment? Quels ont été les éléments facilitants?

Question 7**15 min**

Qu'est-ce qui pourrait être fait pour améliorer le soutien aux familles, ainsi que votre appui vis-à-vis de celles-ci?

Conclusion et déclusion**10 min**

FAMILLES

Objectif d'évaluation 2

Mesurer la qualité des collaborations familles/intervenants : écoute des familles qui donne des transformations concrètes à la lumière de ce qui a été entendu.

Méthodologie :

Un (1) groupe de huit (8) parents ou patients maximum – différents publics cibles famille.

Durée des rencontres : 1 h 30 à 2 h.

Détails public cible :

Groupe familles :

1. Participants aux ateliers *Planetree*.
2. Patients-experts, pôle consultatif.
3. Patients-ressource des groupes de travail.

Indicateurs à évaluer avec les familles :

Est-ce que MUSCO permet de renforcer « l'empowerment » des familles (capacités et opportunités de collaborations) ?

- Sentiment d'être mieux informé.
- Sentiment d'être mieux formé.
- Perception des familles sur la façon dont les professionnels les accueillent.
- Perception des familles sur la prise en compte de leur parole – est-elle bien au cœur de l'Initiative ? Est-elle suffisamment entendue ?
- Quelles applications concrètes à la suite de l'avis donné par les familles ?

Déroulement (90 à 120 min)

Accueil

10 min

Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1

5 min

Quel est votre lien avec l'Initiative MUSCO en termes de collaboration ? De quelle façon y prenez-vous part ?

Question 2

15 min

Comment vous sentez-vous accueillis par les professionnels au sein de l'Initiative MUSCO ? Avez-vous le sentiment que votre parole est entendue et prise en compte ?

Sous-questions : Vous sentez-vous inclus dans les décisions prises ?

Quelle est la qualité de lien que vous avez avec les professionnels grâce à l'Initiative MUSCO ?

Question 3**15 min**

Pouvez-vous partager des applications concrètes mises en place à la suite de l'avis donné par des familles ? Si oui, lesquelles ?

Question 4**15 min**

Pensez-vous que ces collaborations vous permettent d'être mieux informés, formés ? Si oui, pourquoi, comment ? Sous-question : Quels effets cela a sur votre expérience ?

Question 5**15 min**

Vous sentez-vous mieux outillés ? Si oui, sur quels sujets ? Dans quelles conditions ?

Question 6**15 min**

Identifiez-vous des pistes de solutions pour l'un ou plusieurs des thèmes partagés durant la rencontre ?

Sous-questions : Qu'est-ce qui pourrait être fait pour améliorer votre implication dans les processus de décisions ?

Conclusion et déclusion**10 min**

INTERVENANTS

Objectif d'évaluation 2

Mesurer la qualité des collaborations familles/intervenants : écoute des familles qui donne des transformations concrètes à la lumière de ce qui a été entendu.

Méthodologie :

Un (1) groupe de huit (8) intervenants terrains impliqués auprès des familles.
Durée des rencontres : 1 h 30 à 2 h.

Détails public cible :

Groupe de professionnels en contact avec les familles (médecins, personnel administratif, assistants...) :

1. Assistantes de recherche URCO.
2. Professionnels — événement PC.
3. Intervenants des groupes de travail ou patients-ressource.
4. Intervenants — ateliers *Planetree*.
5. Comité plénier.
6. CTI.

Indicateurs à évaluer avec les intervenants :

Est-ce que MUSCO permet de renforcer la qualité de la collaboration avec les familles ?

- Perception des intervenants sur l'apport des familles dans les projets (évolution de la perception, craintes au début et maintenant, facteurs facilitants)
- Quelles applications concrètes à la suite de l'avis donné par les familles ?

Déroulement (120 min)

Accueil

10 min

Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1

5 min

Quel est votre lien avec l'Initiative MUSCO en termes de collaboration ? De quelle façon y prenez-vous part ?

Question 2

15 min

Comment percevez-vous l'implication des familles dans les différents projets ? Avez-vous noté des changements ?

Question 3

15 min

Quels ont été les facteurs facilitants de ces nouvelles collaborations ?

Question 4**15 min**

Pouvez-vous partager des applications concrètes mises en place à la suite de l'avis donné par des familles ? Si oui, lesquelles ?

Sous-question : Quels effets cela a eus sur vos pratiques ?

Question 5**15 min**

Qu'est-ce que cela apporte de nouveau dans votre pratique ? Comment a évolué votre perception sur l'implication des familles dans les projets ?

Question 6**15 min**

De quelles façons les nouvelles pratiques, induites par l'Initiative MUSCO, favorisent « l'*empowerment* » des familles dans leur expérience au sein des établissements ?

Sous-questions : Comment incluez-vous les familles dans les processus de prises de décision ? Quels effets ces collaborations ont sur leur expérience ?

Question 7**15 min**

Identifiez-vous des pistes de solutions pour l'un ou plusieurs des thèmes partagés durant la rencontre ?

Conclusion et déclusion**10 min**

INTERVENANTS

Objectif d'évaluation 3

Mesurer les transformations induites dans les pratiques des professionnels.

Méthodologie :

Un (1) groupe de huit (8) professionnels.

Durée des rencontres : 1 h 30 à 2 h.

Détails public cible :

Professionnels en contact avec les familles (médecins, personnel administratif, assistants...) :

1. Assistantes de recherche URCO.
2. Médecins – différents projets.
3. Infirmières et services des soins infirmiers – différents projets.
4. Professionnels – événement PC.
5. Résidents formation *Bootcamp*.
6. Praticiens – livre interactif.

Indicateurs à évaluer :

Est-ce que MUSCO contribue à l'amélioration des pratiques centrées sur les besoins des patients ?

- Perception des intervenants de mieux connaître/comprendre les besoins ?
- Amélioration de pratiques ? Lesquelles ? Comment ? Grâce à quoi ?
- Perception des intervenants de savoir dépasser les savoirs théoriques en se centrant sur les besoins du patient (apport expérientiel) ?

Déroulement (90 à 120 min)

Accueil **10 min**

Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1 **5 min**

Quel est votre lien avec l'Initiative MUSCO en termes de collaboration ? De quelle façon y prenez-vous part ?

Question 2 **15 min**

De façon générale, quelle est votre perception des effets de l'Initiative MUSCO dans la vie des familles ?

Question 3 **15 min**

Avez-vous le sentiment que cette Initiative vous permet de mieux connaître et comprendre les besoins des patients ? Si oui, comment ?

Question 4**25 min**

Observez-vous une amélioration dans vos pratiques orientées vers les besoins des patients ? Si oui, lesquelles ? Comment s'appliquent-elles et grâce à quoi ?

Sous-question : Avez-vous le sentiment de développer la capacité de dépasser les savoirs théoriques en vous centrant sur les besoins du patient ? Si oui, de quelles façons le constatez-vous ?

Qu'avez-vous constaté comme évolution en termes de pratiques, depuis le lancement de l'Initiative MUSCO au sein des établissements, permettant de faciliter la vie des patients et leurs familles ?

Question 5**25 min**

Identifiez-vous des pistes de solutions pour l'un ou plusieurs des thèmes partagés durant la rencontre ?

Identifiez-vous des freins et des facilitateurs ?

Conclusion et décluseion**10 min**

B. VOLET COLLABORATIONS

PERSONNES IMPLIQUÉES DANS LE PILOTAGE DE L'INITIATIVE

Objectif d'évaluation 4

- Mesurer la transformation des façons de travailler ensemble et les effets dans leur pratique : climat de collaboration, création de liens, effets sur les pratiques.
- Mesurer la perception qu'ils ont des relations avec les autres partenaires externes.
- Identifier les facilitateurs et les freins aux collaborations ainsi que des pistes de solutions concrètes.

Méthodologie :

Un (1) groupe de huit à dix (8-10) personnes maximum avec les personnes impliquées dans les comités (pilotage de l'Initiative) – suivi d'un questionnaire en ligne pour préciser certains éléments, affiner et positionner certains avis.

Durée : 1 h 30 à 2 h.

Entrevues individuelles avec les directions d'établissement, les fondations hospitalières et la Fondation ML Saputo pour creuser sur les relations avec les autres partenaires, les facilitateurs et les freins aux collaborations

Détails public cible :

Groupe de discussion avec les intervenants :

- Intervenants impliqués dans le pilotage de l'Initiative (comités).
- Intervenants impliqués dans les groupes de travail.

Entrevues individuelles :

- Directions des établissements.
- Fondations hospitalières.
- Fondation FML Saputo.

1. Groupe de discussion

Indicateurs à évaluer avec le groupe de discussion :

Qualité des interactions interétablissements et interdisciplinaires :

- Implication des intervenants dans les actions.
- Appels vers les autres établissements pour s'inspirer et s'améliorer.
- Intérêt envers ce qui passe dans les autres établissements.
- Climat convivial entre les intervenants.
- Maintien des comités dans le temps : présences répétées, engagement.
- Perception de tous les intervenants sur la façon dont ils sont intégrés.
- Expression des idées, peu importe le statut.
- Représentativité pas sur les postes, mais sur la variété des expertises.
- Partage de chiffres, données, informations (oser être transparent).

Qualité des interactions avec les partenaires externes :

- Participation aux actions des partenaires externes.
- Implication dans les groupes de travail.

Sollicitations reçues de la part des partenaires du réseau de la santé pour des collaborations ? Nature et nombre ?

Déroulement (120 min)

Accueil **10 min**

Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1 **5 min**

Comment participez-vous à l'Initiative (actions, groupes de travail, comité)

Question 2 **15 min**

Quels types de liens avez-vous créés avec les autres partenaires grâce à l'Initiative MUSCO ?

Question 3 **20 min**

Quels effets ces liens ont sur votre pratique ?

Question 4 **20 min**

Comment trouvez-vous le climat de collaboration (climat dans les rencontres, place et posture de chacun) ?

Question 5 et 6 **30 min**

Qu'est-ce qui facilite ces collaborations ?

Qu'est-ce qui freine ces collaborations, ou les points et vigilances ?

Question 7

15 min

Ce qui pourrait être fait pour améliorer les collaborations ?

Conclusion et déclusion

5 min

2. Questionnaire en ligne pour les participants au groupe de discussion

	Tout à fait d'accord	D'accord	En désaccord	Pas du tout d'accord	Ne s'applique pas
1. Je participe activement aux actions, aux groupes de travail ou aux comités MUSCO.					
2. Je note une amélioration du partage d'information, de données et de chiffres entre les partenaires.					
3. Ma participation à MUSCO m'a permis d'avoir une meilleure connaissance de l'expertise respective de chacun des acteurs.					
4. À partir de l'Initiative MUSCO, j'ai développé de nouvelle(s) collaboration(s).					
5. J'ai créé des liens de confiance avec certains membres du comité.					
6. Je note une amélioration des besoins répondus aux familles.					
7. Je note une amélioration de l'expérience des patients et des familles.					
8. Est-ce que vous recevez des sollicitations de collaborations avec les partenaires externes du réseau de la santé? Si oui, quel nombre et de quelle nature sont ces demandes?					
9. Avez-vous des commentaires					

3. Entrevues individuelles – directions et fondations

Indicateurs à évaluer lors des entrevues individuelles :

Est-ce que MUSCO permet une transformation positive de la collaboration interétablissement ?

- Partage de chiffres, données, informations (oser être transparent).
- Ils échangent avec les établissements partenaires (briser les silos).
- Ils développent des ententes, des protocoles, outils communs et partagés.
- Expression des idées, peu importe le statut.
- Représentativité pas sur les postes, mais sur la variété des expertises et l'équité des établissements.

Quelles leçons peuvent être tirées du modèle de collaboration MUSCO ?

- Conditions de succès d'une Initiative de ce genre.

Déroulement (60 min)

Accueil : Mise en contexte sur l'Initiative MUSCO et l'évaluation.

Question 1

Comment participez-vous à l'Initiative MUSCO (actions, groupes de travail, comité) ?

Question 2

Savez-vous si votre établissement a créé des liens avec les autres partenaires grâce à l'Initiative MUSCO ? Si oui, quels types de liens ?

Question 3

Comment trouvez-vous le climat de collaboration (climat dans les rencontres, place et posture de chacun) ?

Question 4

Est-ce que vous recevez des sollicitations de collaborations avec les partenaires externes du réseau de la santé ? Si oui, quel nombre et de quelle nature sont ces demandes ?

Question 5

Dans l'Initiative MUSCO, qu'est-ce qui facilite les collaborations ?

Question 6

Qu'est-ce qui freine les collaborations, ou les points et vigilances ?

Question 7

Ce qui pourrait être fait pour améliorer les collaborations ?

Conclusion et déclusion

PARTENAIRES EXTERNES

Objectif d'évaluation 5

- Mesurer la participation des acteurs externes à l'Initiative et la répercussion sur les pratiques.
- Mesurer et qualifier les interactions et collaborations des organismes communautaires avec les 4 établissements.

Méthodologie :

12 entrevues téléphoniques maximum avec les différents acteurs :

- 5 personnes des partenaires des groupes de travail.
- 3 personnes des organisations qui travaillent avec le CRME.
- 4 personnes qui ont participé au projet PC.

60 min maximum.

Détails du public cible :

- Organismes communautaires partenaires du réseau de la santé (projets au sein du CRME, journée PC).
- Autres partenaires impliqués dans des groupes de travail (Centre MB Mackay, équipe de recherche MyWay, Meilleur Monde, *Planetree*).

Indicateurs à évaluer :

Est-ce que MUSCO permet de renforcer la qualité de la collaboration avec les partenaires externes ?

- Les partenaires reçoivent des appels des établissements pour des collaborations ?

Est-ce que la qualité de la collaboration avec les familles au sein de MUSCO est reconnue ?

- Perception des partenaires externes sur la collaboration avec les familles.

Quelles applications concrètes à la suite de l'avis donné par les familles ? Mise en place de mesures concrètes ou explications de pourquoi on ne peut pas appliquer : seulement Meilleur Monde et *Planetree*.

Déroulement (60 min)

Accueil : Mise en contexte sur l'Initiative MUSCO et l'évaluation

Question 1

Comment participez-vous à l'Initiative MUSCO (actions, groupes de travail, comité) ?

Question 2

Est-ce que votre organisation a créé des liens avec des partenaires de l'Initiative MUSCO ? Si oui, lesquels et comment ?

Sous-question : Est-ce que vous recevez des appels d'établissement pour des partenariats ?

Est-ce que cette collaboration permet de faire émerger d'autres opportunités de collaboration ?

Question 3

Quelle est, à date, votre expérience en termes de qualité de collaboration ? Quelle répercussion/effet a l'Initiative MUSCO dans vos actions ?

Question 4

À partir de votre vécu, comment qualifiez-vous la collaboration avec les familles au sein de l'Initiative MUSCO ?

Question 5 (*question pour Planetree et Meilleur monde uniquement – objectif 2*)

Pouvez-vous partager des applications concrètes mises en place à la suite de l'avis donné par des familles ? Si oui, lesquelles ?

Sous-question : Quels effets cela a eus sur vos pratiques ?

Questions 6 et 7

Dans l'Initiative MUSCO, qu'est-ce qui facilite les collaborations ?

Qu'est-ce qui freine les collaborations, ou les points et vigilances ?

Question 8

Qu'est-ce qui pourrait être fait pour améliorer les collaborations ?

Conclusion et déclusion

ÉQUIPE MUSCO

Objectif d'évaluation 4

- Mesurer la transformation des façons de travailler ensemble et les effets dans leur pratique : climat de collaboration, création de liens, effets sur les pratiques.
- Mesurer la perception qu'ils ont des relations avec les autres partenaires externes.
- Identifier les facilitateurs et les freins aux collaborations ainsi que des pistes de solutions concrètes.

Méthodologie :

1 groupe avec l'équipe MUSCO.

Durée : 2 h.

Détails public cible :

Groupe de discussion avec l'équipe MUSCO (ressources partagées) :

- CTI.
- Conseillère en génétique.
- Gestionnaire.
- Chargée de projets et communications.

Indicateurs à évaluer :

Est-ce que MUSCO permet de renforcer la qualité de la collaboration interétablissement et interdisciplinaire ?

- Expression des idées, peu importe le statut.
- Représentativité pas sur les postes, mais sur la variété des expertises et l'équité des établissements.

Objectif d'évaluation 6

Mesurer la reproduction du modèle pour d'autres clientèles : signatures d'ententes, mise en place d'actions.

Méthodologie :

Dans le même groupe de discussion que pour l'objectif 4.

Indicateurs à évaluer :

Quelles leçons peuvent être tirées du modèle de collaboration MUSCO ?

- Conditions de succès d'une Initiative de ce genre.
- Intérêt pour la reproduction du modèle pour d'autres clientèles : signatures d'ententes, mise en place d'action ?

Déroulement (120 min)

Accueil **5 min**

Inclusion et règles de vie

Question 1 **5 min**

Comment participez-vous à l'Initiative MUSCO (actions, groupes de travail, comité) ?

Question 2 **20 min**

Comment trouvez-vous le climat de collaboration (climat dans les rencontres, place et posture de chacun, expression des idées, impact des statuts) ?

Question 3 et 4 **30 min**

Qu'est-ce qui facilite ces collaborations ?

Qu'est-ce qui freine ces collaborations, ou les points et vigilances ?

Question 5 **15 min**

Qu'est-ce qui pourrait être fait pour améliorer les collaborations ?

Question 6 **20 min**

À votre connaissance est-ce que l'Initiative MUSCO a stimulé un intérêt ou favorisé la signature d'ententes ou la mise en place d'actions similaires pour d'autres clientèles ?

Si oui, parlez-nous-en.

Question 7 **15 min**

À votre avis, quelles sont les trois (3) conditions de succès d'une telle initiative ?

Conclusion et déclusion **10 min**