



MUSCO

IMPACT REPORT

Executive Summary | January 2022

Written by

Aurélie Vigné and Solène Tanguay



Team commissioned to conduct the Impact Study of MUSCO

Isabelle Mercieca and Kristel de Knibber,
Group Development Advisors

[Coopérative de développement Niska](#)

KEY POINTS

The following findings emerge with regard to **MUSCO's impact on families**:

- **Quality of support provided/received:** Little direct impact is seen, but shared resources and new tools/systems facilitate care and support.
- **The power of the involvement of families:** There is a growing awareness among families of the hospital system and its many processes, which allows them to feel more comfortable about engaging in their care trajectory. However, taking their voice into account should be more deeply rooted in the practices of professionals.
- **Professional practices focused on the needs of families:** A few examples of improvements were identified, including new resources and trainings to better understand the needs of families and to better interact with them.

The following findings emerge with regard to **MUSCO's impact on collaborations**:

- **Inter-institutional collaboration:** The climate of collaboration has evolved, but it remains hampered by internal and external factors. A review of the actors involved and the level of involvement is desired and a better understanding of MUSCO is required.
- **Quality of collaborations with external actors:** External partners note an openness to collaboration and benefit from networking opportunities with the hospital community, but collaboration remains constrained by contextual and political factors. Greater integration is desired.
- **The MUSCO collaboration model:** While MUSCO is attracting interest in being expanded to other clienteles, the work must first and foremost continue in order to draw more promising conclusions. The foundations of the Initiative are in place, but the transformation still requires time.

With a view to continuous improvement, these 13 recommendations should be considered:

The place of families:

1. Optimize the understanding of needs through better representation of families
2. Continue the work to improve the trajectory of patients

Projects as such:

3. Prioritize projects and decisions according to families' needs
4. Strengthen collaborator commitment through better communication
5. Promote the development of skills and the sharing of learning through better dissemination of project monitoring and results
6. Make major changes in professional practices to generate a concrete impact in the trajectory of families

The functioning of the collective steering

7. Optimize governance to maintain engagement
8. Open to other sectors to ensure an impact on the full life trajectory

Organizational cultures

9. Seek to reduce the complexity of procedures, regulations and administrative constraints
10. Establish a culture of collaboration and support this cultural change
11. Promote cooperation dynamics at the institutional level

Initiative and Project Funding

12. Review the funding allocation and reporting process
13. Ensure the sustainability of the actions carried out

SUMMARY

MANDATE

The objective of the evaluation process is to assess the effects and impact of the MUSCO Initiative. Specifically, this evaluation aims to :

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

METHODOLOGY

An Evaluation Committee composed of various key players (stakeholders, partners, families, etc.) was involved in the different stages of the evaluation process. The evaluation strategy was built on the basis of the MUSCO Initiative's Theory of Change and is divided into two major components : 1) effects on patients and their families and 2) impact on collaborative practices. Responses have been collected from 49 collaborators (families, professionals, management, foundations, external partners) from June to September 2021, either through individual interviews or through virtual focus groups. Following the data collection, the evaluation committee participated in the co-analysis of the results, allowing the prioritization of the identified issues. Then, 23 MUSCO collaborators participated in workshops to develop recommendations.

RESULTS : Impact on patients/families

Does MUSCO **strengthen the quality of support offered to patient-families?**

It is difficult to observe the impact on families, since MUSCO works more in the background with health professionals. Nevertheless, patient follow-up and management is facilitated by resources shared between institutions (MUSCO Inter-establishment Navigators and MUSCO genetic counsellor) and by the creation of new tools (e.g. digital quality of life questionnaires).

In order to continue improving the quality of support, it is essential to take the needs of families more into consideration and to facilitate access to clinical data, which remains a major obstacle.

Does MUSCO **empower families?**

Certain MUSCO projects allow for families to have a better understanding of the hospital environment and to raise awareness of their lack of knowledge of the resources available outside the institutions, which helps them to further engage in their care trajectory.

The families involved in the Initiative feel that their opinions are taken into account, but the professionals' awareness of the possible contribution of families needs to be further developed, and families are not always available to get involved.

The presence of the MUSCO Inter-establishment Navigators, the discussion spaces created (subcommittees), the very nature of certain projects and the sustained coordination efforts to involve families are important assets for strengthening the power of their involvement (flexible schedules, virtual meetings, support and neutrality of the MUSCO coordination team).

Does MUSCO contribute **to improving professional practices focused on the needs of patients/families?**

Some developments were reported in this evaluation, but are not a reflection of the projects as a whole.

For example, the new resources developed in terms of personnel, equipment or technologies contribute to improving care and services and to having a better knowledge of families' needs (diagnoses, follow-ups, access to information, exchanges between professionals, etc.). Also, several proposed training activities allow for the improvement of practices with regard to interactions with families.

RESULTS: Impact on collaborations

Does MUSCO positively **transform inter-establishment collaboration (between the 4 partner centers)?**

Overall, the climate of collaboration has improved. There is greater openness and mutual trust. The desire to collaborate and to align procedures between institutions has been strengthened and in some respects has become a reality, and there is a better understanding of the issues and the relevance of the Initiative. The MUSCO coordination team and the support of managers are important assets in this transformation.

However, this transformation is hampered by many internal and external factors: different organizational cultures, regulations, procedures and bureaucracy, relational history, funding mechanisms, the complexity of the Initiative, egos, competition, and the pandemic.

In a context where collaborators are overwhelmed, it would be relevant to review the level of involvement requested and to identify the most relevant actors to involve (prioritize impact rather than representativeness and consider the effect of double-talk). Increased understanding of MUSCO and visibility of results will also help drive the transformation.

Does MUSCO help **strengthen the quality of collaboration with external partners?**

Partners outside MUSCO notice a greater openness to collaborate and appreciate this opportunity to get involved. The Initiative does not particularly impact their practices, but it offers them (community, school, etc.) interesting networking opportunities with the hospital environment. MUSCO exercises positive leadership in terms of collaboration by creating spaces for exchange, promoting collaborative values and thanks to the presence of MUSCO Inter-establishment Navigators who facilitate liaison.

However, collaboration is hampered by many contextual and political factors: bureaucratic realities and rigidities, mistrust and political issues, lack of time and turnover in human resources. External actors feel that MUSCO is a fairly closed initiative about which they have little visibility. Better knowledge and integration of external actors would strengthen collaboration.

What **lessons** can be learned from the **MUSCO collaborative model**?

The collaborators see MUSCO as a pilot project to be expanded to other clientele. However, for the time being, the level of collaboration and its actual impacts do not seem clear enough to draw meaningful conclusions. The work - which is long-term and accepted as such by the majority - must continue. However, several success factors have been identified: the presence and role of a coordinating team, the mobilization of teams towards a change in culture, the shared vision and mutual benefits, feedback and continuous improvement.

CHALLENGES AND RECOMMENDATIONS

CHALLENGES	RECOMMENDATIONS
	(C) = MUSCO collaborator recommendations (N) = Niska team recommendations

The place of families

1 - Optimize understanding of needs through better representation of families	Improve the process of recruiting and accompanying families (C) Communicate better with families about the Initiative (C) Further reach out to families more effectively, in creative ways (N) Explore how families want to be involved (N) Clarify what they think makes a real difference in their journey (N)
2 - Continue to work on improving the patient trajectory	Build on human resources shared between institutions (C) Optimize communication mechanisms between MUSCO's partner centers and stakeholders, as well as external ones (C) Provide families with more tools (C) Improve communications with partners (C) Focus on better inter-professional collaboration centred on the needs of families (each family is different) (C)

The projects as such

3 - Prioritize projects and decisions based on family needs	Leverage the MUSCO Inter-establishment Navigators to raise awareness of family needs among stakeholders (C) Develop discussion forums with families of various profiles to better understand their needs (C) Raise collaborator awareness of the importance of involving families (C)
4 - Strengthen collaborator engagement through better communication	Make collaborators more accountable for results (C) Communicate the common values and mission focused on the needs of families (C) Provide more opportunities for involvement for collaborators who have an interest (C) Improve communication tools to further disseminate the progress, impact and network of collaborators involved in MUSCO (C)

<p>5 - Promote the development of skills and the sharing of learning through better dissemination of project monitoring and results</p>	<p>Ensure a better understanding and a global view of all the Initiative's projects for all collaborators (C) Create opportunities for follow-up and exchanges between collaborators, with managers and considering interdisciplinarity (C) Disseminate progress more widely through conferences, among others (C)</p>
<p>6 - Make major transformations in professional practices to generate a concrete impact in the trajectory of families</p>	<p>Disseminate the Initiative to more actors to have a more complete effect (C) Involve the stakeholders concerned upstream from the start of the projects to benefit from their expertise (C) Make professionals aware of the importance of being open and informed about practices elsewhere (C) Create a Montreal center that goes beyond the individuality of each institution (C)</p>

The functioning of the collective steering

<p>7 - Optimizing governance to maintain commitment</p>	<p>Review the relevance of governance committees and their roles: Steering Committee, Executive Committee, plenary Committee, Advisory pole (C) Streamline approval processes (C) Make meetings more dynamic to encourage active participation in decisions (C) Clarify who is accountable for results (C) Provide more opportunities for stakeholder involvement (C) Adjust the governance model to serve the Initiative and patients/families / Explore circular governance models (N)</p>
<p>8 - Open to other sectors to ensure an impact on the entire life trajectory</p>	<p>Focus on key players (all levels of management, physicians, MUSCO Inter-establishment Navigators) (C) Invite other stakeholders to become involved (rehabilitation centers, community) (C) Recognize the role of external players and support them in their mission (C) Consider the child's trajectory more broadly (C) Create opportunities to meet with external players (C) Move towards a holistic vision of the human being (N) Make professionals aware of the issues faced by families beyond the "medical" (N)</p>

Organizational cultures

<p>9 - Seek to reduce procedures, regulations and administrative constraints</p>	<p>Work on policies and regulations that promote inter-establishment collaboration (C) Improve understanding of the respective operations and roles of field actors in each center (C) Define formal communication processes (C)</p>
---	--

<p>10 - Establish a culture of collaboration and support this cultural change</p>	<p>Involve the different professional bodies and management levels (C) Involve families and encourage their involvement (C) Define, value and communicate the importance and benefits of collaboration (C) Support collaboration and implement official, clear and consistent collaborative practices (information distributed to families, involvement of Inter-establishment Navigators, etc.) (C) Anchor the culture of collaboration in the institutions with the support of senior management and give the necessary latitude to stakeholders to collaborate (C) Focus collaboration around the needs of families (C) Empower stakeholders to identify and implement change / Rely on front-line individuals (N)</p>
<p>11 - Promote cooperation dynamics at the institutional level</p>	<p>Create spaces for exchange to encourage networking and develop mutual trust (C) Structure collaboration mechanisms (collaboration office, collaborative practices, etc.) (C) Identify the levers and adjust the mechanisms that will facilitate collective work (N)</p>

Funding for the initiative and projects

<p>12 - Review the funding allocation and reporting process</p>	<p>Create spaces for discussion to question the objectives and impact on patients and families (C) Structure accountability by project, not just by facility (C) Balance accountability with desired changes (N) Revise the strategic plan to ensure that projects that truly meet the needs of families and achieve the desired impact are prioritized (N) If the Initiative is renewed, collectively develop a strategic plan including a financial request for Phase 2 of the project (N)</p>
<p>13 - Ensure the sustainability of the actions undertaken</p>	<p>Highlight the concrete benefits of MUSCO (C) Ensure that projects maintain their impact without additional funding (equip current resources rather than create new needs) (C) Focus on the sustainability of the projects themselves and not MUSCO as a whole (C) Plan the budget from a sustainability perspective and be proactive in seeking resources to cover operating costs (C) Prioritize efforts and projects according to defined criteria (real impact on patients/families, ministerial priorities, available funding) (C) Consider the sustainability of collaborative practices (not just from a financial perspective) (C)</p>