

# PRACTICAL GUIDE

*to provide a framework and promote the  
integration of Patient-Resources  
within the working groups  
of the MUSCO projects*

February 2021



## MUSCO

A FRIEND TO CHILDREN WITH MUSCULOSKELETAL  
DISORDERS AND THEIR FAMILIES

A CONCERTED INITIATIVE  
TO TRANSFORM PATIENT  
CARE AND SERVICES



**Hôpitaux Shriners  
pour enfants®  
Shriners Hospitals  
for Children®**  
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# FOREWORD

## **Purpose of this Guide :**

To provide a framework and promote the integration of Patient-Resources within the working groups of projects originating from MUSCO.

The purpose of this Guide emerged from a reality: professionals and families are not necessarily used to working together to carry out joint projects. However, MUSCO has set the goal of integrating the voices of families at the core of its activities with the goal of improving their quality of life. The involvement of patients, parents or caregivers in the Initiative's projects thus ensures that we have an accurate vision of the needs of families.

In light of this reality, it seemed important to organize a workshop to equip MUSCO collaborators, both families and professionals for this collaboration. Numerous collaborators met to discuss and reflect on best practices in terms of integration and teamwork. The fruit of these reflections made it possible to produce this Guide, which is intended to be a tool for parents, physicians, managers, practitioners, or any other stakeholders within the MUSCO working groups.

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# CONTEXT

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## MUSCO OVERVIEW

### In a few words...

The MUSCO initiative is a collaborative effort between the major pediatric institutions that are the 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. It is a concerted initiative to transform the care and services offered to families.

### Why MUSCO?

MUSCO is born out of an observation: children who suffer from musculoskeletal disorders and who require complex care too often face problems of access throughout their care journey and in their social integration. Faced with this situation, these institutions have decided to join forces to develop an inter-institutional collaboration giving life to more than twenty different projects.

### Which objectives?

Each of the partners share the desire to make life easier for the patients and families who attend their institution and wish to make a difference to improve their quality of life. It's about ensuring that the right patients have access to the right institutions at the right time for the best care. The goal is to transform care and services through an **inclusive, innovative, transdisciplinary** and **collaborative** approach.

## Four values guide the orientation of MUSCO's projects

### INCLUSION

Place patients and their families at the heart of the actions, for a continuous improvement of their well-being.

### COLLABORATION

Engage in a collaborative approach based on constant communication and respect for each person's mission.

### INTERDISCIPLINARITY

Implement concrete actions to improve care and services based on a translational, inter-institutional, intersectoral and transdisciplinary approach.

### INNOVATION

Develop innovative projects to encourage the involvement of other financial partners and guarantee the sustainability of the Initiative, without however reproducing existing projects.

## The voice of families at the core of the Initiative

MUSCO has a single goal: To improve the living conditions of patients and their families. To achieve this goal, it is essential to understand the needs of families. Thus, the governance of the Initiative and its mode of operation for the realization of projects place the voice of families at the center of discussions. In order to fully understand the involvement of families within the MUSCO Initiative, certain definitions need to be clarified.

**MUSCO Advisory Pole** Formal entity of MUSCO's governance with the primary mandate of **advising on the Initiative's orientations**. It is made up of Patient-Experts who currently meet 3 times a year.

**Patient-Expert** The Patient-Experts present a significant experience and a relevant profile directly related to the objectives set by the Initiative. It should be noted that a Patient-Expert can also be a Patient-Resource.

**MUSCO Working group** A team formed specifically for the **realization of MUSCO projects**. Each of the working groups is supervised by a clearly identified project leader who guides the team members towards the achievement of the project's objectives. Several MUSCO working groups involve Patient-Resources and stakeholders from the Initiative's various partner institutions. The working groups meet at frequencies that they themselves define according to the needs of the project.

**Patient-Resource** Parent, patient or caregiver, member of a MUSCO working group. The Patient-Resources actively contribute to the realization of the Initiative's projects as collaborators.

In light of these definitions, it is clear that the integration of families into the Initiative is an approach that must be understood and supported by all MUSCO collaborators. This is the *raison d'être* of this Practical Guide.

## CO-CREATION PROCESS

This Guide is the result of discussions that took place during a workshop on the integration of Patient-Resources organized by MUSCO, the content of which was prepared in collaboration with the Réseau Planetree Francophone (RFP). RFP contributed to the creation of the workshop and also to the development of this Guide.

### Partner in the approach : Réseau Planetree Francophone

The [Réseau Planetree Francophone](#) (RPF) brings together people who receive and those who offer care and services to create the best possible experience for all. The organization's expertise contributes to structuring person-centered care and services to achieve the ultimate vision: **Humanizing care and services**. It positions itself as a catalyst for **human-centred** care and service management.



"It is through a real partnership with patients and their families that we discover the reality of these people and improve their living conditions. This partnership underpins an organizational transformation in which each of the stakeholders, patients and their families, clinicians and managers, are empowered to become inseparable parts of the solution."

Marie-Claude Poulin, Organizational Advisor, Réseau Planetree Francophone  
(Partner for the design of the MUSCO workshop)

## MUSCO Workshop on the Integration of Patient-Resources



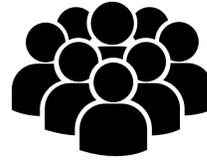
**2 workshops**

November 18-24, 2020



**4 questions**

(List in Appendix 1)



**25 participants**

(List in Appendix 2)



**1 Practical Guide**

in 4 phases

### About the process

Participants were invited to one of the two 1.5-hour workshop sessions. The workshop was divided into 5 steps to foster an atmosphere of sharing and open dialogue.

**1**

Presentation  
of objectives



**2**

Inclusion  
activity



**3**

Division into  
discussions groups



**4**

Plenary



**5**

Closing  
activity

During the discussion groups, each group had 3 questions to discuss (from the 4 questions in Appendix 1). Subsequently, a spokesperson identified within each group was given the mandate to synthesize the discussion points raised for each of the questions during the large group plenary.

The workshop questions were designed to reflect the core values of the MUSCO Initiative, namely: **inclusion**, **collaboration**, **interdisciplinarity**, and **innovation**, and to address the sustainability perspective of the Initiative itself.

## About the participants

Since the voice of families needs to be at the center of the Initiative's activities, it was important to include families in these workshops, so that they could both speak up and be heard by professionals. Notably, Patient-Experts from the MUSCO Advisory Pole were present, as well as current Patient-Resources who are members of the MUSCO working groups, or even other professionals who have a child with special needs.

The list of participants (Appendix 1) reflects the variety of profiles who brought important points to the discussion table. Thus, this guide consolidates various perspectives regarding the integration of Patient-Resources.

## A parallel impact...

The workshop was also an opportunity to bring together a multitude of stakeholders involved in MUSCO projects. The experience thus made it possible to achieve a parallel objective: to clarify MUSCO and mobilize its partners towards a common vision of collaboration between institutions and with families. Indeed, the workshop benefited the professionals, because as they reflected on the integration of Patient-Resources, they also reflected on their own integration within the working groups. A double objective was therefore achieved.

"I gained a better understanding of the MUSCO structure and projects [by participating in the workshop on the integration of Patient-Resources]."

Dr. Philippe Campeau, Clinical Assistant Professor, CHU Sainte-Justine  
Research Centre

(Participant to the MUSCO workshop)

## OVERALL CONTRIBUTION OF THE GUIDE

### Purpose and content

The purpose of this guide is to prepare MUSCO working groups for the integration of Patient-Resources. It provides best practices to ensure optimal integration of Patient-Resources at all phases of a project. To this end, the Guide is divided into four Practical Sheets covering the following steps:

- **Practical sheet # 1**: Planning phase
- **Practical sheet # 2**: Start-up phase
- **Practical sheet # 3**: Execution phase
- **Practical sheet # 4**: Finalization phase

Although this guide is specifically intended for MUSCO project working groups, it brings together several good practices about integration that may be generalized. Hence this guide proposes good practices for optimizing the collaborative and interdisciplinary work atmosphere in general. This is in fact where MUSCO's main expertise lies, as it acts as a facilitator between the teams of the Initiative's partner institutions.

### Key contacts for working groups

#### **MUSCO Shared Resources' Team**

The Initiative is supported by shared resources within the 4 partner institutions to facilitate collaborations all across. This team is composed of the following members: MUSCO Manager, MUSCO Inter-Establishment Navigator, MUSCO Communications and Project Manager, MUSCO Genetic Counselor (refer to Appendix 3 for the mandate of each).

#### **Project Leader**

Each project is guided by a project leader who is designated at the planning phase. This person's mission is to guide the discussions and tasks towards achieving the project objectives. This person also sits on the Initiative's Full Committee<sup>1</sup> to share the progress of the project for which he or she is responsible among all MUSCO collaborators.

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<sup>1</sup> MUSCO's Full Committee is a governance entity that brings together all project leaders.

## What challenges does this guide address?

In line with MUSCO's four core values and the sustainability of the Initiative and of the actions undertaken, several challenges can be identified with regard to the integration of Patient-Resources. This Guide aims to identify possible solutions to these various challenges described below.

### **INCLUSION CHALLENGES**

**THE INTEGRATION OF PATIENT-RESOURCES IS NEW TO MANY MEMBERS OF EXISTING WORKING GROUPS..**

Several working groups may have already been established and have begun the execution of projects. These groups will welcome Patient-Resources into their team along the way and will therefore need to prepare an inclusive atmosphere for their new colleagues. Furthermore, not all professionals are accustomed to working with families.

### **COLLABORATION CHALLENGES**

**WORKING GROUPS BRING TOGETHER INDIVIDUALS WITH DIFFERENT ASPIRATIONS AND PERSONAL BACKGROUNDS.**

MUSCO working groups are made up of individuals from a variety of backgrounds. Each individual's interests may be divergent, particularly with respect to the aspiration to innovate. Some may have the ambition to move towards riskier avenues, while others wish to focus on proven paths. Also, interpersonal relationships can impact discussions, not to mention the potential history between members. These factors can affect collaboration within the group.

### **INTERDISCIPLINARITY CHALLENGES**

**THE WORKING GROUPS BRING TOGETHER PROFESSIONALS FROM DIFFERENT INSTITUTIONS, DIFFERENT HIERARCHICAL LEVELS AND DIFFERENT AREAS OF EXPERTISE.**

The work culture varies between the four MUSCO partner institutions, both in terms of methods and language used. Thus, professionals are confronted with different cultures in the scope of MUSCO projects. Normally, teams are not accustomed to collaborating with partners from other institutions or even with external partners.

In addition, professionals are not always familiar with the realities of their peers, which can make it more difficult for the members of a working group to connect and communicate amongst each other. Moreover, professionals do not all share the same areas of interest: each brings his or her field of expertise, but does not necessarily recognize the contribution of the other at first glance.

## **INNOVATION CHALLENGES**

### **MUSCO'S PROJECTS ARE FOCUSED ON INNOVATION.**

Within MUSCO, it is not a question of reinventing something that already exists. Therefore, the need to keep a watchful eye on what is being done elsewhere is particularly important. Innovative projects also imply that the current network is not necessarily structured to maintain new activities beyond the projects, hence the importance of the sustainability challenges described below.

MUSCO also represents an opportunity to explore a new collaborative model potentially transposable to the healthcare network in general. The lessons learned from the Initiative are thus very important.

## **SUSTAINABILITY CHALLENGES**

### **MUSCO IS AN INITIATIVE IN CONSTANT EVOLUTION.**

The Initiative is planned for an initial period of 5 years. Hence, it is essential to reflect on the sustainability of projects and collaborations originating from MUSCO. The initiative is constantly evolving and the projects still need to be defined over time. The existence of the working groups and the duration of the projects therefore remain variable.

**"The workshop was a very good initiative to improve [...] patient experiences, the involvement of key people in the workshop was very beneficial, a big thank you to the organizing team."**

**Toufik Baziz, Information Services Manager**  
Shriners Hospitals for Children - Canada  
(Participant to the MUSCO workshop)

## PRACTICAL SHEET #1: PLANNING PHASE

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*How to plan the beginning of the relationship with Patient-Resources?*

The planning phase involves Patient-Resource recruitment and integration activities. The following best practices mainly involve the MUSCO shared resources team in collaboration with the project leader. These guidelines help define who the Patient-Resources are, how they should be recruited and integrated and when.

### LEGEND



Activities conducted by the MUSCO shared resource team

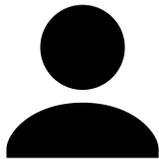


Useful resources

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### WHO?

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#### Ideal Patient-Resource Characteristics

- Interest in a long-term involvement
- No conflicts of interest or hidden personal interests
- Ability to take a step back to keep a higher level perspective and avoid personal frustration
- Significant experience with the project's environment

#### Composition of the Working Groups

- Ensure a diversity in Patient-Resources (age, socio-professional situation, profiles: parents, children, adolescents, etc.)
  - Seek to have more than one Patient-Resource around the table so that it is less intimidating for them, knowing that they represent a community and not an individuality
  - Ensure a diversity in members of the working group as a whole to ensure representation of stakeholders and to bring together divergent opinions
  - Encourage Patient-Resources to invite other partners to join the discussions
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## HOW?

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### Adequate Recruitment Process

- Ensure that the involvement of Patient-Resources is a voluntary decision and that recruitment is not forced
- Ideally, solicit families already being followed within the Initiative or already members of existing focus groups in the Initiative's immediate circle
- Preferably, the contact should be made through a professional who already has a relationship of trust with the family



In the majority of cases, Patient-Resources in the MUSCO working groups are recruited through one of the MUSCO shared resources or as a result of the parent's or patient's participation in an activity organized as part of one of the MUSCO projects. Many are already involved in the MUSCO Advisory Pole.

### Preparation of the Working Groups

- Inform the working group of the arrival of the Patient-Resource ahead of time
- Educate healthcare professionals and clinicians on the integration of Patient-Resources



This Practical Guide is a useful tool to raise awareness about good practices among working group members.

### Preparation of the Patient-Resource

- Allow the Patient-Resource to connect with one or two people up front so that he or she has a familiar face to refer to later on
- Provide information to the Patient-Resource on the nature of the project, progress and challenges so that he or she has the same level of information as the rest of the group



An initial meeting must be planned by the MUSCO team between the Patient-Resource and the person leading the working group in order to establish a first contact.



Work is carried out upstream by the MUSCO team in order to clearly define the orientation of the projects. A project sheet is then written to clarify the objectives, deliverables and constraints related to each project. This is a good tool for communicating the nature of the project.

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## WHEN?

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### Ideal Timing for Recruitment

- Avoid holidays and the back-to-school period
- Focus on recruitment during an activity organized as part of one of the MUSCO projects
- Take advantage of the moments when one of the projects from MUSCO is concrete so that potential Patient-Resources can see the result of a project in which they could have been involved

### Ideal Timing for Integration

- Integrate the Patient-Resource as early as possible in the process, if possible from the beginning of the project right from the design phase in order to integrate his or her opinion into the project definition



Although the execution of several projects began before Patient-Resources could be integrated into the working groups, the MUSCO Advisory Pole contributed to the design of many of the Initiative's projects.

## PRACTICAL SHEET #2: START-UP PHASE

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*How to properly launch the involvement of the Patient-Resources within the working groups?*

The start-up phase concerns the actions that must be undertaken from the very beginning of the project. The good practices listed below are mainly carried out by the project leader, with the contribution of the members of the working group. The aim is to clarify the guidelines for collaboration and to make the working group aware of the contribution of the Patient-Resources.

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### WHO?

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#### Members' Contribution

- Ensure that the role of the Patient-Resource is real and that it is not a showcase, consider the contribution of families as a major added value
- Consider the Patient-Resources as teammates, integrating them in the same way as all other collaborators
- Define the role of Patient-Resources in terms of function to highlight their abilities and expertise
- Ensure that he or she is integrated into the project planning, each person must contribute to the content of the reflections
- Highlight each expertise and its contribution, keeping in mind that together we go further
- Distinguish the experience of each Patient-Resource and avoid talking about a homogeneous group of patients because the involvement of each one comes from a personal process
- Each member is a representative who needs to share information within his or her community, beyond the working group

#### Roles and Responsibilities

- Begin the discussions with a round table to explain the function of each person in the group, but also in life in general
  - Define the role of each member ahead of time
  - Identify a charismatic leader who can animate the relational side of the project, someone who brings people together
  - Define the role of the Patient-Resource and what is expected of him/her, define clear tasks to be accomplished to empower the Patient-Resource
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## WHAT?

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### Mandate

- Put the project in context and ensure that all participants are familiar with the same information and are aware of the same challenges
- Explain the purpose of the project to obtain everyone's buy-in
- Establish a clear timeline defining the duration of the desired commitment
- Ensure consistency between the requested workload and the time commitment originally envisioned
- Include all members in all facets of the project (design, development, assessment, outreach, transposition)

### Shared Goals

- Set a collective mission and vision
- Agree on this common goal at the beginning of the project
- Remember that patients and their families are at the heart of all decisions
- For this common goal, detail and share short, medium and long term objectives
- Define the objectives in collaboration with the Patient-Resource in order to keep his or her interest at the heart of the project

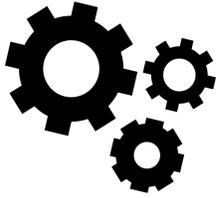
### Expectations

- Clarify team members' expectations and manage them, specifying what they can expect to get in return for their involvement
- Elaborate what is expected of team members
- Ensure that project results meet the original objectives to avoid frustration or disappointment
- Consider overlapping goals (individual and collective) and ensure that everyone's personal aspirations are developed
- Provide a reason to be present at the meetings, find a way to "feed" participants and create a win-win situation for all

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## HOW?

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### Project Management

- Breakdown the project into more easily attainable tasks, with short-term objectives to empower each participant
- Clearly explain the methodology and processes of the project
- Dig deeper into certain aspects in smaller groups of experts, not always in the larger group setting
- Arrive with starting points to stimulate brainstorming
- Clearly assign tasks to each person at the end of each meeting
- Have a specific agenda with objectives, deliverables and timelines

### Mode of Operation

- Send a Doodle sufficiently in advance to take into account the availability of everyone
- Set meeting times at moments that are favourable for Patient-Resources, avoiding work or school hours and trying to solicit their help during times when they are already waiting at the hospital if it is convenient for them (waiting room, during hospitalization, etc.).
- Take advantage of virtual meeting platforms to avoid travel
- Send a clear agenda to everyone prior to the meetings and set objectives for each meeting
- Offer coffee and snacks when the meetings are in person
- Define rules of conduct within the working group

## PRACTICAL SHEET #3: EXECUTION PHASE

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*How to ensure a smooth collaboration with Patient-Resources?*

The execution phase concerns the actions to be undertaken as well as the attitude to adopt throughout the collaboration. More specifically, it is the phase where the Patient-Resources work concretely within the work group, the phase where the activities take place in order to achieve the objectives. Good practices in terms of communication, recognition and team atmosphere involve all members of the working group, but must be encouraged by the project leader.

"This workshop emphasized the importance of gathering everyone's contributions. The main elements I have learned are to include the patient from the beginning of a project and ensure that he is well integrated, that roles must be well identified and clear, and to recognize that the patient adds major value to the project."

Elena Guadagno, Research Project Manager, Harvey E. Beardmore  
Division of Pediatric Surgery, Montreal Children's Hospital  
(Participant to the MUSCO workshop)

### LEGEND



Activities conducted by the MUSCO shared resource team



Useful resources

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## COMMUNICATION

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### Common Language

- Limit the use of medical jargon, present information in clear terms without oversimplifying
- Avoid the use of acronyms
- Make sure to speak in the language that is understood by the participants, bilingual if necessary

### Means of Communication

- Accommodate the Patient-Resource regarding the choice of means of communication (email, Zoom, in person, etc.).
- Work on shared documents in real time through platforms such as Google Drive or OneDrive
- Ensure that all participants have access to common documentation and know where to find it
- Use collaborative softwares to track tasks: to-do lists, schedules, dashboards (ex: Monday.com, Trello.com, etc.)
- Test other means of communication, sometimes more informal, to communicate more effectively (ex: social networks).

### Frequency of Discussions

- Keep all members informed of project progress through regular communication to encourage engagement
- Write minutes following the meetings and send them to everyone
- Ensure that all participants know who to refer to at all times and that they have the opportunity to establish contact at any time to keep the dialogue open



The MUSCO team can share with you a simple and efficient reporting template to write down the meeting minutes. It includes a section to record the actions to be taken following each meeting and the people responsible for each action.

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## RECOGNITION

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### Collective Appreciation

- Share any positive feedback and results in regard to the project to everyone
- Publicize results and impacts when possible
- Demonstrate that progress is being made, regardless of the degree, because small victories are equally important
- Value the group's contribution in a global way, because the idea is to win together



The MUSO team proudly shares the progress of the various projects through its newsletter which is distributed a few times a year. Many will be solicited to share the small and big victories associated with their project.

### Individual Appreciation

- Define how everyone's participation has an impact
- Value the contribution of each individual and acknowledge participation, do not forget the importance of saying thank you
- Provide concrete examples of the impact of each member and highlight the good calls
- Ensure timely recognition of individuals

### Two-Way Constructive Feedback

- Demonstrate that discussions lead to concrete actions
- Integrate feedback and comments, even if it means modifying the project based on discussions
- Where suggestions are not retained, explain why it is not possible to incorporate them
- Question members about their level of satisfaction in order to adjust the way things are done, if necessary, through satisfaction questionnaires or feedback meetings

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## TEAM ATMOSPHERE

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### Openness and Receptivity

- Avoid putting too much pressure on Patient-Resources and focus on the broader issues
- Acknowledge the stress experienced by families and consider their emotional load
- Let go of preconceptions or traditional ways of doing things and be open to change
- Encourage kindness and avoid judgment
- Name the difficulties, fears, realities and avoid ego wars

### Equality

- Remove hierarchy, putting all members on the same level of equality and remembering that no one is more important than the other
- Ensure a balance in speaking and take the time to ask the Patient-Resources for their input
- Tend towards abandoning the use of titles

### Team Spirit

- Take a proper moment to say hello at the beginning of each meeting
- Reiterate the common goal to avoid personal agendas
- Do not arrive with decisions made in advance without consulting the group
- Plan more informal opportunities to allow all members to connect easily (e.g. 5@7)
- Monitor the evolution of the work atmosphere and make changes if required
- Be patient because working in an interdisciplinary group requires a certain time to adapt

## PRACTICAL SHEET #4: FINALIZATION PHASE

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*How to finalize the relationship with Patient-Resources in a positive way? What next?*

The finalization phase concerns the actions to be carried out in the closing phase of the project. At this stage, the project leader is responsible for closing the project. It is also important to do a quick recap of the experience with the Patient-Resource and to discuss other potential future involvement. In the scope of the Initiative, MUSCO's shared resources take charge of this step.

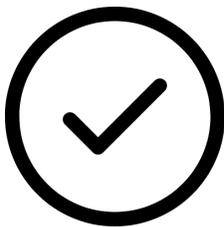
"The professionalism and listening skills of the MUSCO team and the open-mindedness of the participants [...] contributed positively to my experience as a Patient-Resource [within the *Cerebral Palsy, Let's Talk About It!* working group]."

Stéphanie Renaud, Nathan's mother

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### PROJECT CLOSURE

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#### End of Project

- Organize a post-mortem meeting with all members involved, including the Patient-Resources
- Formally thank all participants involved by reiterating the impact of the work accomplished

#### What next?

- Keep all collaborators informed of the project's progress over time because they remain ambassadors even after the project is completed
- Maintain a link with all members and don't hesitate to stay in touch
- Promote the added value of involving Patient-Resources in projects and share their experience



It may be relevant to share a contact sheet with all collaborators to encourage them to maintain relationships beyond the project.

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## MAINTAINING THE RELATIONSHIP

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### Continuous Improvement

- Ask about the overall appreciation of the Patient-Resource in regard to his or her experience
- Gather Patient-Resource comments and suggestions of areas for improvement
- Share the key feedback points from the Patient-Resource with the project leader
- Share avenues for improvement within the community of collaborators



After the last meeting of the project, a discussion is organized with the Patient-Resource by the MUSCO team.



This Guide is a living tool that will be nourished by the concrete experiences of the working groups and the Patient-Resources.

### What next?

- Explore the Patient-Resource's willingness to get involved again in another project if he or she wishes to do so and if his or her agenda allows it
- Invite the Patient-Resource to share his or her experience with his or her family and friends to promote good practices and initiate contacts with other potential Patient-Resources
- Solicit testimonials from the Patient-Resource in order to value his or her contribution and better promote the experience

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#### LEGEND



Activities conducted by the MUSCO shared resource team



Useful resources

## APPENDICES

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### Appendix 1 : Workshop Discussion Questions

#### QUESTION 1 : INCLUSION

Given that patients and their families are major partners of the MUSCO Initiative, how can we promote their inclusion in the working groups?

#### QUESTION 2 : COLLABORATION

What are the winning conditions for collaboration within working groups?

#### QUESTION 3 : INTERDISCIPLINARITY

How can we ensure that there is interdisciplinarity within the working groups and that the experience and contribution of each person is considered beyond the status or profession of each participant?

#### QUESTION 4 : SUSTAINABILITY\*

How can we secure the presence and interest of participants in the various working groups over the medium term (especially of Patient-Resources)?

\*Although sustainability is not one of the Initiative's four core values, this question provided an opportunity to explore good practices in a more concrete way for participants. The value of INNOVATION, which is not a question in itself, was nevertheless discussed through this question, since the sustainability of projects is closely linked to the notion of innovation.

## Appendix 2 : List of Workshop Participants

**Carl-Éric Aubin**, Executive and Scientific Director of the TransMedTech Institute

**Caroline Marie Fidalgo**, Alex Olivier's mother, Patient-Expert, member of the MUSCO Advisory Pole

**Chantal Damas**, Clinical Programs Continuous Improvement Coordinator, Shriners Hospitals for Children - Canada

**Elena Guadagno**, Research Project Manager, Harvey E. Beardmore Division of Pediatric Surgery, Montreal Children's Hospital

**Elizabeth Clark**, Rehabilitation R&D Coordinator, Occupational Therapist, Marie Enfant Rehabilitation Centre

**Evelyne Diot**, Senior Advisor, Philanthropic Development and Major Gifts, CHU Sainte-Justine Foundation

**Kathryn Fournier**, Director / Executive of Quality, Evaluation, Performance and Ethics, Shriners Hospitals for Children - Canada

**Linda Moreau**, Nia's mother, Patient-Expert, member of the MUSCO Advisory Pole

**Lise Roche**, Programs' Director, Mirella and Lino Saputo Foundation

**Marie Beauséjour**, Professor and Researcher, Department of surgery, Université de Montréal

**Marjolaine Roy-Beaudry**, Clinical Research Coordinator URCO, CHU Sainte-Justine Research Center

**Martin Sasseville**, Research Professional, Centre de recherche Charles-Le Moyne - Saguenay-Lac-Saint-Jean sur les innovations en santé

**Nathalie Jourdain**, Clinical Research Coordinator URCO, CHU Sainte-Justine Research Center

**Noemi Dahan-Oliel**, Clinician Scientist, Shriners Hospitals for Children - Canada

**Patrick Desmarais**, Analyst in Software Development, CHU Sainte-Justine

**Philippe Campeau**, Assistant Clinical Professor, CHU Sainte-Justine Research Center

**Pierre-François Gautier**, Ergonomist, CHU Sainte-Justine

**Soraya Barchi**, Clinical Research Coordinator URCO, CHU Sainte-Justine Research Centre

**Stefan Parent**, Deputy Head, Research Axis, Musculoskeletal Diseases and Rehabilitation, CHU Sainte-Justine Research Center

**Stéphanie Renaud**, Nathan's mother, Patient-Resource, member of the working group for the event "*Cerebral Palsy, Let's Talk About It!*" (2020 edition)

**Sylvain Caron**, Project Manager Computerized Clinical Record and Clinical Analyst, CHU Sainte-Justine

**Tina del Duca**, Assistant Manager of Rehabilitation, Marie Enfant Rehabilitation Centre

**Toufik Baziz**, Information Services Manager, Shriners Hospitals for Children - Canada

**Valancy Miranda**, MUSCO Genetic Counselor

**Valérie Gascon**, Quality, Evaluation, Performance and Ethics Advisor, Shriners Hospitals for Children - Canada

## Appendix 3 : MUSCO Shared Resource Team

### **MUSCO Manager**

Mandate : To ensure the progress of the Initiative as a whole and within the various projects and to strengthen the main orientations and governance of MUSCO.

### **MUSCO Communications and Project Manager**

Mandate : To support the coordination of projects stemming from MUSCO and to ensure the outreach and dissemination of the Initiative's progress as a whole.

### **MUSCO Inter-Establishment Navigator**

Mandate : To support patients and their families in their care journey by facilitating discussions and collaborations within MUSCO's partner institutions.

### **MUSCO Genetic Counselor\***

Mandate : To explain genetic outcomes and their implications to patients and families, meet their needs and support them in their decisions and care pathways.

\*The MUSCO Genetic Counselor is a shared resource between the CHU Sainte-Justine and the Shriners Hospitals for Children - Canada only.

# THANK YOU !



# MUSCO



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Hospital  
McGill University  
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