

PRACTICAL GUIDE

The first steps toward
patient-family experience-based
project evaluation

February 2022



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®

Canada

Hôpital de Montréal
pour enfants
Centre universitaire
de santé McGill



Montreal Children's
Hospital
McGill University
Health Centre



PREFACE

Purpose of this Guide:

To educate MUSCO collaborators on the importance of considering the patient-family experience in the evaluation of their project

Like the [guide written following the Integration workshop for Patients-Resources](#) (conducted in February 2021 within the framework of MUSCO and in collaboration with the Planetree Francophone Network), this document aims to synthesize the exchanges between collaborators who were able to attend another MUSCO workshop, this time conducted to raise awareness of the importance of considering the patient-family experience when evaluating a project. When teams conduct a project within MUSCO, regardless of the topic or departments involved, that project will ultimately impact patients and their families and it is therefore essential to consider their experience to measure the effects of the project, and to do so with continuous improvement and sustainability in mind, and to make adjustments, as needed, throughout the process.

Recall that the workshops organized in the context of MUSCO are part of a Training Plan with a *FAMILIES* component designed to equip staff and strengthen their collaborative practices with families. The general idea tends toward the creation of a community of practice to share viewpoints and fuel reflections.

Despite still busy agendas, many collaborators once again voluntarily registered for this non-mandatory workshop, and were thus able to have a reflexive approach to their projects, exchanging best practices in terms of the family experience, but also in terms of evaluation and partnership with patients and their families. The richness of these exchanges is reflected in this Guide, which like the previous one is intended to be a tool for all : patients, families, physicians, managers, stakeholders, or any other stakeholders within the MUSCO working groups and beyond.

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CONTEXT

MUSCO OVERVIEW

In a few words...

The **MUSCO** initiative is a collaboration 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 **MUS**culoskeletal disorders and require **CO**mplex 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 shares 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 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 being taken, 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.

CO-CREATION PROCESS

Working group and partnership with NISKA

This Guide is the result of discussions that took place during a workshop whose content was prepared in collaboration with a working group composed of representatives from each MUSCO partner institution, and with the support of an external partner, NISKA, which contributed to both the creation and facilitation of the workshop, but also to the writing of this Guide.

The members of the working group came from the quality and performance departments of each institution, but also from the departments responsible for the partnership between patients, families and caregivers. This was the first time that one of the MUSCO projects brought together this category of professionals in a virtual working table.

Partner [NISKA](#), meanwhile, is a cooperative working on the notion of organizational development and systems complexity, and promotes a participatory and democratic approach both within its organization and in its mandates or with its partners. NISKA also worked with the MUSCO coordination team and collaborators involved to measure the overall impact of the Initiative on families and professionals, with results and recommendations reflected in [an impact report](#) that will serve as the basis for the Initiative's further development.



MUSCO workshop: procedure



2 workshops

February 15-16, 2022



4 axes addressed

projects and or large
project themes



20 participants

(List in Appendix 1)

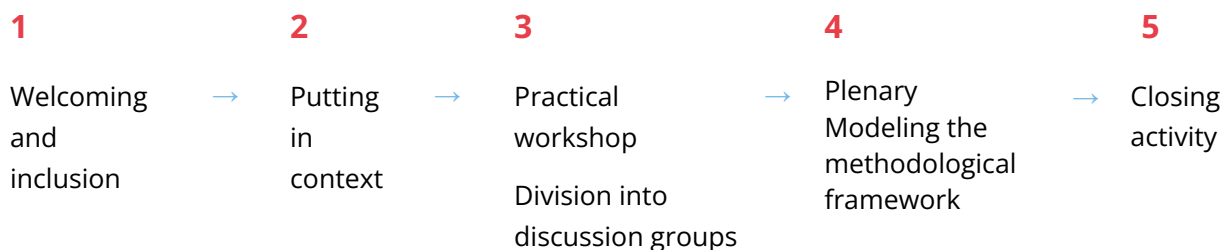


1 Guide

with theoretical
notions and
practical
application

About the process

Participants were invited to one of two 2-hour workshop sessions. Each workshop was divided into several steps:



The groups were formed in relation to the different MUSCO projects with regard to the nature of the participants enrolled (involvement in one of the MUSCO projects and or potential interest in one of these projects), each of whom was invited to formulate evaluative questions with regard to the project and or theme identified within their group.

Thus, the following MUSCO projects and or themes were addressed:

- [Patient Trajectory](#) Project
- [Educational Technology](#) Project
- [Relay](#) Project
- Clinical-research axis (including the [URCO](#) project - [Clinical Research Unit in Orthopaedics](#), the [Genetic Counsellor](#) project and the [Clinical Research Support in Rehabilitation](#) project)

Following the group discussions, a rapporteur was responsible for presenting the exchanges and discussions raised in plenary.

About the participants

All MUSCO employees were invited to register. Therefore, there were participants of all types and categories of jobs:

- patients and families
- volunteer services coordinator
- psychoeducator
- research professionals
- clinical research associates
- genetic counselor
- inter-establishment navigator
- program coordinator
- service designer
- manager
- director
- representatives of foundations

The list of participants found in (Appendix 1) reflects this diversity of profiles, which contributed to the richness of the exchanges.

Parallel impacts

The organization of the workshop allowed the quality and evaluation services to work together on a common project to build a module that did not exist or was poorly developed in the services they offer to teams in the different institutions. This permitted a sharing of perspectives and a better understanding of the mandate carried in each institution.

In addition, talking about impact and the patient experience brought up the topic of partnering with families and raising awareness of each participant. If a patient and/or family is not around the table and not actively participating in the discussions, how do we ensure that their needs are considered? How can we ensure that each person involved is an ambassador for the reality of the families' lives at all times?

WHY EVALUATE AND WHAT IS MY ROLE?

DEFINITION OF THE WORD EVALUATE

When we talk about evaluation, we mean

- to determine, fix, appreciate the value, the price of something, a good, a service offered, a process undertaken, etc.
- to determine approximately the duration, quantity, number, importance of something.

"To evaluate is essentially to make a value judgment about something, based on methodically gathered information, and then to decide what action to take that follows from that judgment and improves what is being evaluated." Franklin Midy

"Evaluation is a learning tool." McConnell Foundation

"Evaluation is the systematic assessment of the design, implementation, or outcomes of an initiative for the purpose of learning or decision making." Canadian Evaluation Society

"A systematic approach to estimating the value of an intervention." Innovative Territories in the Social and Solidarity Economy (TIESS)

WHY EVALUATE

The reasons for evaluation are multiple and complementary:

- Stay focused on the initial intentions, remain centered on the meaning of the action.
- Measuring how far we've come.
- Learn.
- Facilitating management and collective decision making.
- Address the issues that arise along the way.
- Demonstrate relevance.
- To highlight.
- Celebrate successes.

Evaluation creates value!

MY ROLE

It is essential that all the staff involved be champions of the evaluation process and of the patient-family approach. It is often necessary to consider developing a participatory evaluation culture.

Some conditions to be put in place by the evaluation "owner":

- Proceed in a progressive manner. Start "small" with a single evaluation object: the effects of a project, for example.
- Educate employees on the constructive/useful aspect of evaluation.
- Educate staff on the scope of the evaluation based on the patient-family experience.
- Avoid linking the evaluation of projects/activities to the evaluation of the teams developing the project/activity.
- Think about evaluation when formulating project objectives.
- Set up monitoring and evaluation tools.
- Develop the reflex of keeping written records, compiling information, and using it in debriefing exercises.
- Share results to highlight achievements and good works.

THE PURPOSE OF THE EVALUATION

WHAT CAN BE EVALUATED? AT WHAT POINT?

Everything can be evaluated!

The purpose of the evaluation is determined by our original intent:

- What is the intent of our project or collaboration?
- What do we want to learn?
- What do we want this evaluation to do?
- And so what question(s) do we want to answer?
- When can we get this information?

Whether at the start, during or at the finish of the project, the evaluative questions are always relevant to keep the meaning of the action in mind. Moreover, this is a continuous approach, which can be repeated and looped depending on the answers sought.

The effects on the people or organizations reached are assessed and this is done from the perspectives of the different people involved (patients, families, stakeholders, participants, partners, governance members, volunteers, patient-families, etc.).

MORE SPECIFICALLY, HOW DOES THIS RELATE TO THE FAMILY EXPERIENCE?

Why make a connection to the patient-family experience?

The participatory approach promotes :

- Stakeholder ownership of the process.
- A process that is well suited to the context and needs of the organization.
- A richer process that takes into account the views of various stakeholders (co-construction).
- An acceptance of indicators and evaluation criteria.
- The use and distribution of results.

- Implementing the necessary changes.
- Collective learning.
- Democratic values and practices.
- "Empowerment" as the organization and individuals take ownership of the process.
- Discussion among the partners of a project as to the indicators and criteria on which the project should be evaluated, thus promoting a common vision of the project.
- Sometimes the involvement of funders and their awareness of the organization's objectives and ways of doing things as well as the needs of the participants.

How do we relate to the patient-family experience?

- Determine the evaluation approach WITH those involved: involve patients-families in developing the evaluative questions and strategy, as well as in developing the recommendations that will emerge from the analysis.
- Evaluate by consulting directly with the people affected by the object of the evaluation, they are the experts in the field.

THE STEPS OF AN EVALUATION PROCESS

1. Identify the object(s) of evaluation, i.e., define what you want to know

This can be based on the desired impacts of a project. For example, in the case of MUSCO, we can refer to the change paths of the initiative.

2. Develop the survey instrument

It is a matter of determining who can answer our questions, in what way and at what time. At this stage, we ask ourselves how we will collect our information, particularly with regard to the choice of tools (e.g.: logbook, observations, documentation, questionnaire/survey, individual interviews, focus groups). We also develop the data collection protocols based on the choice of tools. Finally, we also determine who is responsible for administering and doing the data collection.

3. Collect the data

This involves implementing data collection mechanisms: questionnaires, interviews, focus groups, collection of quantifiable information...

4. Analyze and interpret data

This step allows for collective learning.

5. Improving action through results

It is important at the end to promote the results to those involved (beneficiaries, stakeholders, decision makers, partners) and publicly as needed.

THE BASIS OF THE PROCESS: THE EVALUATION QUESTION

Through the evaluation questions, the dimensions of the patient-family experience of the project in question should be specified.

It is a question of directing the spotlight on substantive issues, illuminating blind spots, and questioning basic assumptions.

To the extent that everything is questionable (in the sense that any element of the experiment can be questioned - as can its very foundation), one must prioritize the questions and define the scope of what will be effectively investigated and addressed. Evaluative questions that are too specific can miss a central issue.

So what are the most sensitive issues to be tabled where the project is at?

How do you ensure that you ask the questions that will shed light on specific points while maintaining a global view?



Source : Biliz et Diawara (1982).

HOW TO FORMULATE THE QUESTION?

Here is a reference grid with a typology of basic questions¹ to enable a 360 degree evaluation of your project.

Type of evaluation	Type of questions
Need for an analysis of the experience	Ex: What needs of the patient-family experience will the project address?
Design and prototyping of the experience	Ex: What do we retain as essential in the design of the approach? And why?
Monitoring of the experiment	Ex: What evolution did you notice in the different phases of the project?
Process Evaluation	Ex: What was innovative about your process?
Evaluation of results and impacts	Ex: What are the observable results of our project/activity?
Efficiency	Ex: Was the way we worked together optimal in terms of the results obtained?

The idea is to build on these main questions to go further with other sub-questions that appear relevant at this stage of the project.

It is important to formulate open-ended questions that lead to understanding something and qualify it. We use "how," "why," "to what extent," "what is..." etc.

¹ [Source: Adapted from Owen J with Rogers P (1999). Program Evaluation: Forms and Approaches. Sydney: Allen & Unwin/London: Sage UK].

A GOOD EVALUATION QUESTION VERSUS A NOT SO GOOD ONE

Example of a good evaluation question:

What helped you understand the information you received?

This question leads us to evaluate the practices in a certain context and to measure which ones are successful or not.

Example of a lesser evaluative question:

Do you feel that the information you received was sufficient to your understanding of the situation?

This question leads us to draw an assessment of the action: did what we did work or not, but it is a closed question that does not allow us to understand the practices and their impact on the targeted people.

EXAMPLES FROM THE WORKSHOPS

- What needs of the patient-family experience will the project address?
- How have we facilitated patient and family involvement to make their participation more comfortable and fluid?
- How does the technology tool improve the family journey? How does it improve their care experience? How does it meet families' core expectations?
- Does the process help to target the needs of families in the child's overall journey? If so, how?
- What is the experience of the patients-resource? How do patients feel when they are challenged and listened to?
- Do patients-resources feel that their contribution has improved the experience of other families? If so, how has this contribution improved the experience of other families?

AND THEN?

WHAT TO DO WITH MY EVALUATION QUESTION?

- **Mobilize** stakeholders and involve key players
- **Convene** a committee and follow the steps in the evaluation process (p.11)
- **Seek** help from evaluation experts in your institution

ADDITIONAL RESOURCES

Participatory evaluation for collective action:

<https://agirtot.org/thematiques/evaluation-participative/evaluation-participativeen-savoir-plus/>

Developing an evaluative and learning culture:

<https://tiess.ca/developper-une-culture-evaluative-et-apprenante/>

A Practical Guide to Impact :

https://chantier.qc.ca/wp-content/uploads/2018/05/guide_pratique_impact_2018.pdf

Is a useful and mobilizing evaluation possible?

https://communagir.org/medias/2018/04/groupe_travail_reperes_Evaluation.pdf

HOW DOES THIS RELATE TO THE MUSCO IMPACT STUDY?

The study that was conducted with the support of NISKA to measure the impact of the Initiative on families and professionals is a separate process from this workshop. It is a more comprehensive approach that is not about the projects per se but rather about the whole process. However, the two approaches are linked.

The evaluation strategy for MUSCO as a whole was built on the Initiative's theory of change, the details of which can be found in the [impact report](#). In this theory of change, there are two primary and one secondary path of change that define the ultimate long-term goals of MUSCO:

- patients and their families are supported to improve their quality of life, including a fluid experience between facilities;
- communications and collaborations are optimized and become the norm;
- the MUSCO experience is replicable in other contexts.

Thus, the shared vision and ultimate desired change is: "Improve the quality of life for patients and their families." Each evaluative question should move us closer to this mission defined in the overall MUSCO framework.

APPENDICES

Appendix 1: List of workshop Participants

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WHO MADE THE WORKSHOP AND THIS GUIDE POSSIBLE!

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