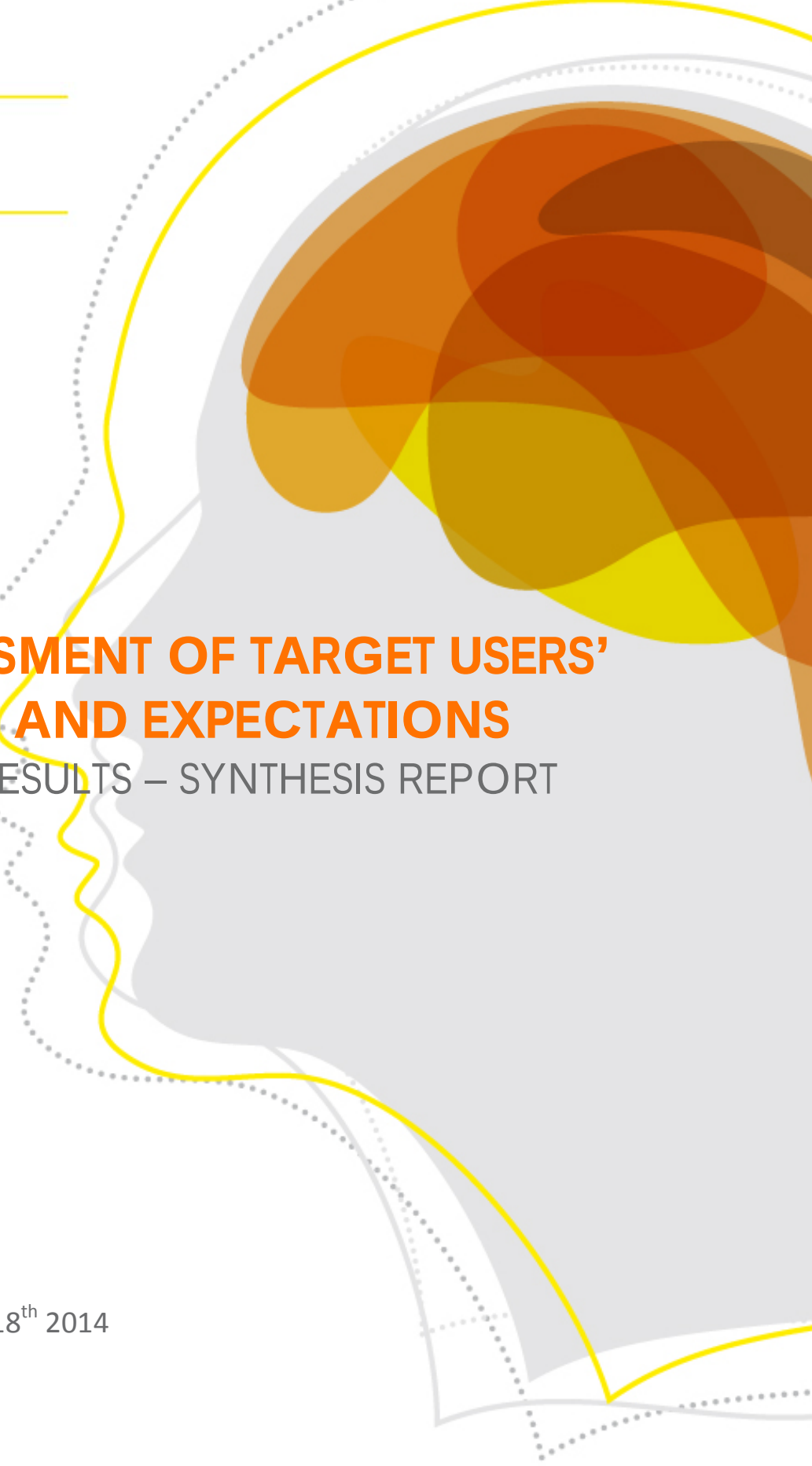
CLINICAL PRACTICE GUIDELINE

FOR THE REHABILITATION OF ADULTS WITH MODERATE TO SEVERE TBI



ASSESSMENT OF TARGET USERS' NEEDS AND EXPECTATIONS

FINAL RESULTS – SYNTHESIS REPORT

September 18th 2014

Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

Institut national d'excellence en santé et en services sociaux
Québec

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Project team:

Catherine Truchon
Project Co-manager
Institut national d'excellence en santé et en services sociaux (INESSS)

Bonnie Swaine
Scientific Co-director
Université de Montréal

Marie-Ève Lamontagne
Researcher
Université Laval

Mario De Bellefeuille
Advisor
Institut national d'excellence en santé et en services sociaux

Anne-Sophie Allaire
Québec Coordinator

Corinne Kagan
Project Co-manager
Ontario Neurotrauma Foundation (ONF)

Dr. Mark Bayley
Scientific Co-director
University Health Network, Toronto

Dr. Shawn Marshall
Researcher
University of Ottawa Research Institute

Ailene Kua
Ontario Coordinator

ABBREVIATIONS

AERDPQ	Association des établissements de réadaptation en déficience physique du Québec
AQESSS	Association québécoise des établissements de santé et de services sociaux
ACF	Acute-care facility
RIIU	Rehabilitation institution with an inpatient unit
RINIU	Rehabilitation institution without an inpatient unit (offering outpatients services only)
INESSS	Institut national d'excellence en santé et en services sociaux
IRDPQ	Institut de réadaptation en déficience physique de Québec
ONF	Ontario Neurotrauma Foundation
MSTBI	Moderate to severe traumatic brain injury

CONTEXT

For the purposes of the project to develop and support the implementation of a clinical practice guideline (CPG) for the rehabilitation of adults with MSTBI, an extensive consultation was held among the tool's intended users of the CPG. These include, managers, coordinators and clinicians who provide rehabilitation services to such patients in acute-care settings (early rehabilitation) or specialized rehabilitation settings (as inpatients and/or outpatients). The primary objective of this consultation was to explore users' perceptions and needs regarding the content, format and implementation of the CPG. More specifically, the objectives of the consultation were to:

1. Evaluate users' perceptions of CPGs (knowledge, acceptance, usefulness, actual use and projected use).
2. Identify users' needs concerning the domains, nature and form of the recommendations required to support the optimal rehabilitation of people with MSTBI.
3. Explore users' perceptions of the actual level of clinical practice and of rehabilitation processes for people with MSTBI compared to the perceived optimal level.
4. Explore users' perceptions and expectations concerning the performance indicators that will accompany the recommendations.
5. Identify users' needs and expectations concerning the implementation of a CPG.

METHODOLOGY

Following approval by the IRDPQ's research ethics board, a consultation was held by means of an online survey (FluidSurvey) between November 11 and December 13, 2013. The managers of early rehabilitation and specialized rehabilitation programs serving MSTBI patients sent the individuals concerned on their teams an e-mail with a link for accessing the survey. Eligible participants had to have had at least 6 months' experience with adults with MSTBI (i.e. work at least two days a week with the patient population); eligible physicians were those working at least one day a week with such patients. The survey was available in English and in French.

The survey was sent to 16 acute care facilities (8 in Québec and 8 in Ontario) and to 32 rehabilitation institutions (15 in Québec and 17 in Ontario). Figures 1 to 3 and Table 1 show the sociodemographic and professional profile of the **487 respondents** who completed the survey. We note a slightly higher proportion of respondents from Québec than Ontario and a relatively heterogeneous distribution by health and social services regions, which was not necessarily proportional to the expected representation from each territory. The breakdown of respondents by practice setting, position and basic professional training generally fits the expected profile in this sector of activity. More than 60% of the respondents had at least 5 years of experience with MSTBI patients.

A detailed report on the methodology and results is presently being drafted.

RESPONDENT PROFILE

N = 487

Figure 1 - Province

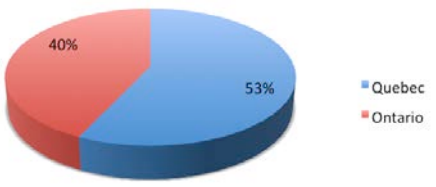


Figure 2 - Gender

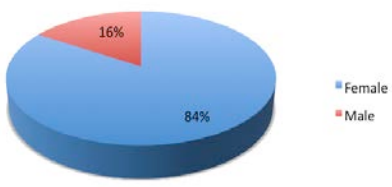


Figure 3 - Position held

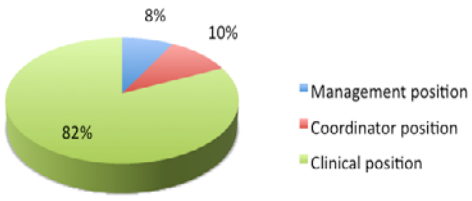


Table 1 Other professional characteristics of the respondents (n = 487)

Characteristic	Frequency (n)	Percentage (%)
Practice setting		
Acute-care facility (ACF) (early rehabilitation)	109	22
Rehabilitation institution with an inpatient unit (RIIU)	256	53
Rehabilitation institution without an inpatient unit (RINIU)	120	25
Missing	2	0
Main area of training		
Occupational therapy	87	18
Physiotherapy	77	16
Psychology	31	6
Neuropsychology	40	8
Social work	49	10
Speech therapy	43	9
Nutrition	4	1
Kinesiology/Physical education	12	2
Special education	24	5
Recreation/Leisure therapy	14	3
Nursing	59	12
Medicine	24	5
Administration	9	2
Other	1	0
Missing	13	3
Years of experience		
1-5	131	27
6-10	108	22
11-15	95	20
16-20	59	12
21 and more	54	11
Missing	40	8
Québec health and social services region		
01 - Bas-Saint-Laurent	22	8
02 - Saguenay–Lac-Saint-Jean	17	7
03 - Capitale-Nationale	31	12
04 - Mauricie et Centre-du-Québec	32	12
05 - Estrie	12	5
06 - Montréal	47	18
07 - Outaouais	5	2
08 - Abitibi-Témiscamingue	5	2
09 - Côte-Nord	6	2
11 - Gaspésie–Îles-de-la-Madeleine	0	0
12 - Chaudière-Appalaches	12	5
13 - Laval	20	8
14 - Lanaudière	12	5
15 - Laurentides	8	3
16 - Montérégie	23	9
Missing	7	2
Ontario health and social services region		
01 - Erie St. Clair	5	3
02 - South West	17	9
03 - Waterloo Wellington	9	5
04 - Hamilton Niagara Haldimand Brant	17	9
05 - Central West	1	1
06 - Mississauga Halton	10	5
07 - Toronto Central	50	26
08 - Central	5	3
09 - Central East	3	1
10 - South East	7	3
11 - Champlain	34	17
12 - North Simcoe Muskoka	0	0
13 - North East	30	15
14 - North West	6	3
Missing	1	0

RESULTS

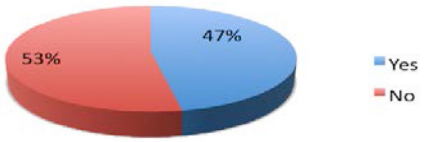
The results of the consultation are presented here in three sections, which correspond to the three areas covered by the survey: the current perception of clinical practice guidelines (CPGs), needs and expectations regarding content, and, lastly, the preferred implementation strategies.

THE CURRENT PERCEPTION OF CLINICAL PRACTICE GUIDELINES

Why consider this? It is well known that users' knowledge of a new intervention or process considerably influences how successfully it will be implemented. It was therefore essential for the project team to learn about and understand clinicians', coordinators' and managers' perceptions and level of knowledge regarding a CPG intended to support the rehabilitation of adults with MSTBI, in order to be able to develop an implementation strategy that meets the users' needs as best possible.

What did the respondents tell us about this? A large proportion of the respondents (53%), both in Ontario and Québec, **were not aware of any CPGs for the rehabilitation of adults with MSTBI** (Figure 4). More respondents in rehabilitation institutions with an inpatient unit (RIIUs) and those that serve outpatients only (RINIUs) were familiar with such resources than those working in acute-care facilities (ACFs) [RIIUs = 50% and RINIUs = 52% compared to ACFs = 32% of respondents]. However, only a minority (34%) of the resources mentioned as CPGs by the respondents actually fit the usual definition of a CPG, the other resources mentioned included clinical programs, specific clinical tools, reference frameworks developed by government agencies, and clinical handbooks.

Figure 4 - I know of at least one CPG that supports the rehabilitation of adults with MSTBI.



In addition, **few respondents presently use CPGs** to guide the rehabilitation of people with MSTBI (see Figure 5). Fewer Québec respondents than Ontario respondents reported using such resources (median of 1 in Québec versus a median of 5 in Ontario on a 10-point Likert scale). Although they use CPGs more often, the Ontario respondents indicated that they feel less equipped to use such resources compared to the Québec respondents. In general, a number of respondents indicated that considerable experience with MSTBI patients can facilitate the use of a CPG. **The lack of specific training on the use of CPGs and different barriers associated with their practice environment are described as obstacles to the use of CPGs**.

Figure 5 - I currently use at least one CPG that supports the rehabilitation of adults with MSTBI

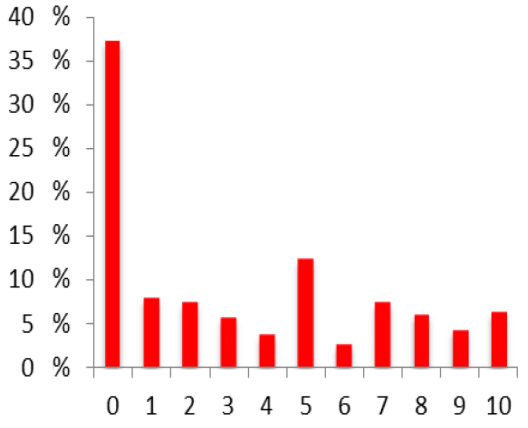
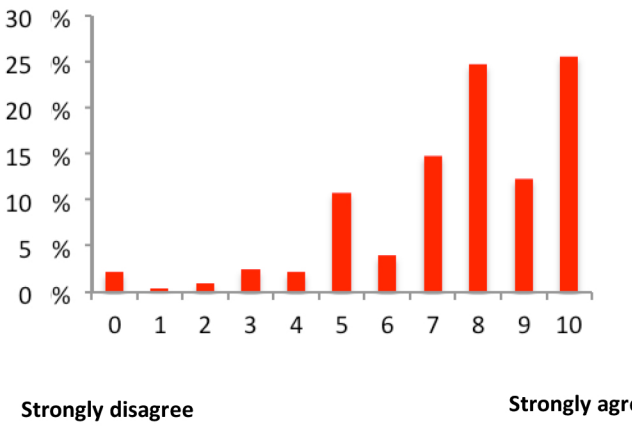


Figure 6 - I believe that a CPG provides a solid knowledge/evidence base to support the rehabilitation of adults with MSTBI



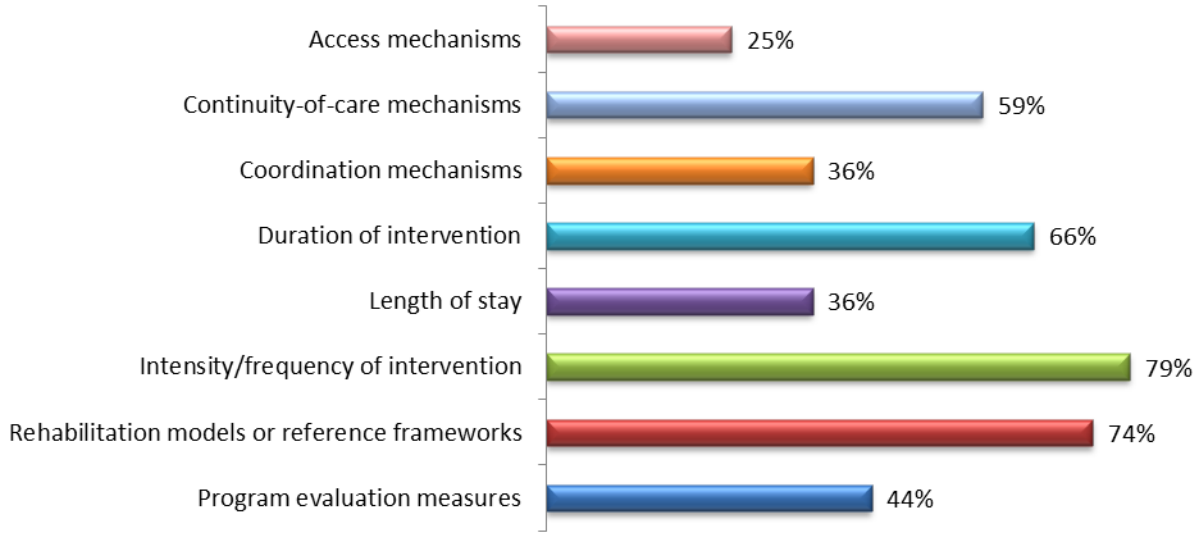
Although they are not very familiar with and make little use of CPGs, most of the **survey respondents feel that CPGs constitute a solid base for supporting the rehabilitation of adults with MSTBI** (see Figure 6). A number of respondents stated that, in their opinion, this type of tool promotes evidence-based interventions and can improve the quality and uniformity of their practice while at the same time making it easier for them to update their knowledge. Lastly, most of the respondents, in all the practice settings and in all the occupational categories (managers, coordinators and clinicians) reported feeling that **the interventions they perform are often in line with best practices**. They indicated several intervention domains in which improvement is more specifically needed, in particular, cognitive impairments, return to work, behaviour problems, interventions for the elderly, and interdisciplinary work.

NEEDS AND EXPECTATIONS REGARDING CONTENT

Why and how to document this aspect. The project team must ensure that the CPG deals with aspects important to the clinicians, coordinators and managers who will use this tool. We therefore regrouped and categorized all of the potential topics identified through a systematic review of the CPGs available in the literature and asked the respondents to indicate which ones were most important to them. The aspects explored in the consultation concerned both the mechanisms and parameters related to service provision as well as clinical interventions for people with MSTBI.

What emerges from this prioritization exercise? With regard to **the mechanisms and parameters of the rehabilitation** services offered to people with MSTBI, the respondents were relatively unanimous. A large majority of respondents expressed interest in the issues of intervention intensity and frequency and rehabilitation models of care (79% and 74%, respectively), but the respondents considered it less important that access mechanisms (25% of respondents), coordination mechanisms (36%) and length of stay (36%) be covered (see Figure 7). In response to an open-ended question, the respondents also expressed the desire that the CPG discuss the best interventions or the best evaluation tools, the organizational structure of rehabilitation, and the interdisciplinary team's role.

Figure 7 - Which mechanisms and parameters of the rehabilitation services offered to adults with MSTBI should be covered in the CPG? (5 priority elements per respondent)

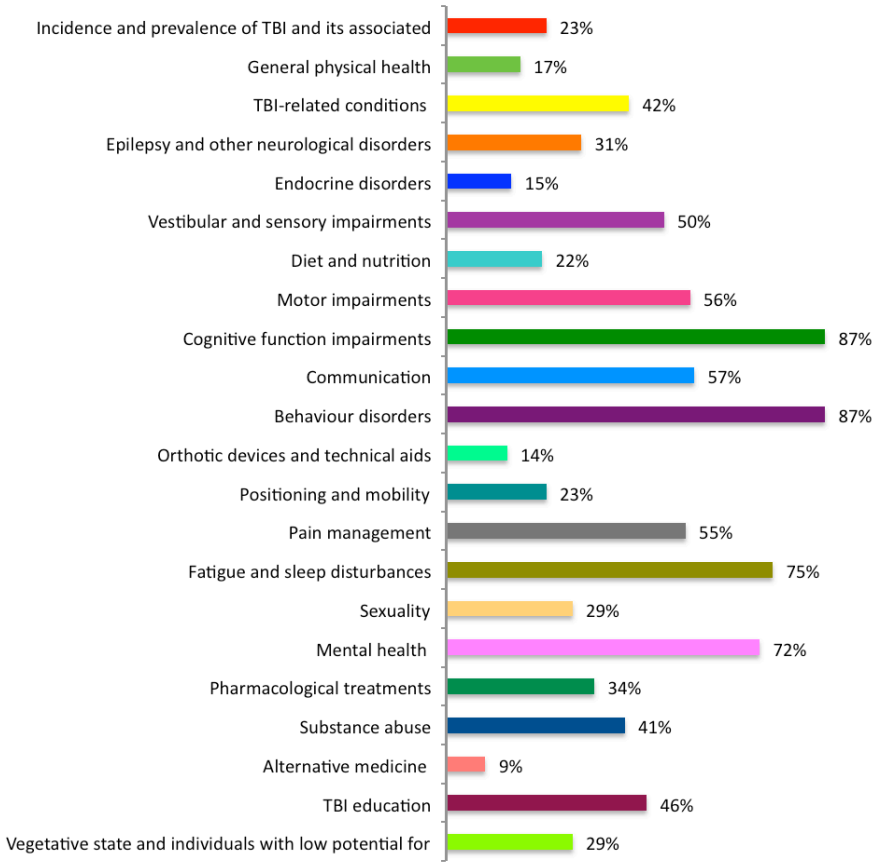


A few differences of interest

- Length of stay was considered more important by the Ontario respondents (48%) than those in Québec (31%) and by the RIIU respondents (43%) than those in the RINIUs (25%).
- Although they generally seemed to be moderately interesting (44%) for all, program evaluation measures were more interesting to the Ontario respondents (54%) than those from Québec (39%).
- On the other hand, proportionately, more Québec respondents expressed an interest in models of care or reference frameworks than Ontario respondents (81% vs. 62%).

With regard to the elements associated more specifically with the **intensive rehabilitation process** (see Figure 8), the respondents indicated the following aspects as being most important: cognitive impairments (87% of the respondents), behaviour problems (87%), fatigue and sleep problems (75%), and mental health problems (72%). Few respondents considered it important that the CPG propose recommendations concerning alternative medicines (9% of the respondents), orthotic devices and technical aids (14%), endocrine disorders (15%) or overall physical health (17%). Again, on this matter, the respondents indicated they would like to be informed of the best interventions and the best evaluation tools to be used..

Figure 8 - Which elements of the intensive rehabilitation process for adults with MSTBI should be covered in the CPG (10 priority elements per respondent)

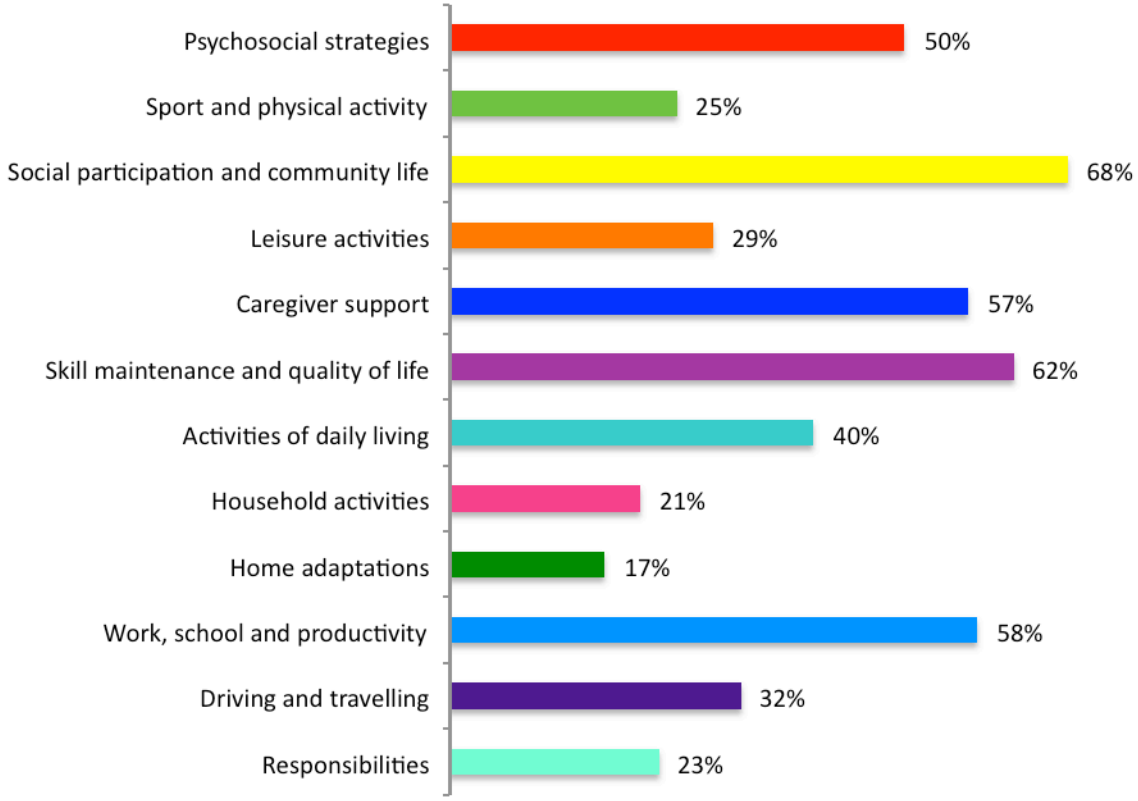


A few differences of interest

- The Ontario respondents showed relatively greater interest than their Québec counterparts in communication (65% for Ontario respondents vs. 52% for Québec respondents), positioning and mobility (35% vs. 16%) and training on TBI (61% vs. 38%).
- On the other hand, the Québec respondents expressed a greater need than their Ontario counterparts with regard to epilepsy and other neurological complications (36% for Québec vs. 22% for Ontario), endocrine disorders (19% vs. 7%), fatigue and sleep disorders (80% vs. 67%), and sexuality (35% vs. 20%).
- The managers expressed greater interest than their clinician and coordinator colleagues in nutrition (43% of the managers vs. 20% of the coordinators and 21% of the clinicians), motor deficits (79% vs. 60% and 53%, respectively) and communication (79% vs. 57% and 54%, respectively).
- The ACF respondents expressed a stronger preference with regard to motor disabilities (70% vs. 51% for RIIUs and 57% for RINIUs) and to positioning and mobility (48% vs. 20% and 9%, respectively).
- Lastly, elements pertaining to mental health were found to be more important to the RINIU respondents than those at ACFs (81% vs. 60%, respectively).

Lastly, on the matter of the social integration phase (see Figure 9), the aspects deemed more important to all of the people consulted were social participation and community life (68%), skill maintenance and quality of life (62%), work, school and productivity (58%), and caregiver support (57%). Home adaptations (17% of respondents), household activities (21%) and responsibilities (23%) were found to be important topics for fewer than 25% of the respondents.

Figure 9 - Which elements of the social rehabilitation and integration process for adults with MSTBI should be covered in the CPG? (5 priority elements per respondent)



A few differences of interest

- The Ontario respondents were more interested in psychosocial strategies (61% vs. 46% of those in Québec) and the activities of daily living (51% vs. 35%), while the Québec respondents attached more importance to leisure activities (34% vs. 22% of those in Ontario), household activities (24% vs. 14%) and responsibilities (30% vs. 10%).
- The ACF respondents seemed more interested in matters pertaining to caregiver support (68% vs. 43% of the RINIU respondents), activities of daily living (63% vs. 30% of the RINIU respondents), and social participation and community life (56% of the ACF respondents vs. 27% of the RIIU and RINIU respondents).
- The ACF respondents were, however, less interested in leisure activities (19% vs. 43% of the RINIU respondents), work, school and productivity (36% vs. 68% of the RINIU respondents) and responsibilities (14% vs. 33% of the RINIU respondents).
- Interestingly, the RINIU respondents expressed significantly less interest in caregiver support (43% vs. 68% of the ACF respondents and 62% of the RIIU respondents).
- However, the RINIU respondents indicated greater interest in sport and physical activity than the ACF and RIIU respondents (38% vs. 24% and 18%, respectively, for the ACF and RIIU respondents).
- The only difference between the occupational categories concerned activities of daily living, an aspect for which the coordinators expressed significantly less interest (17%) than the managers (46% and clinicians (43%).

THE PREFERRED IMPLEMENTATION STRATEGIES

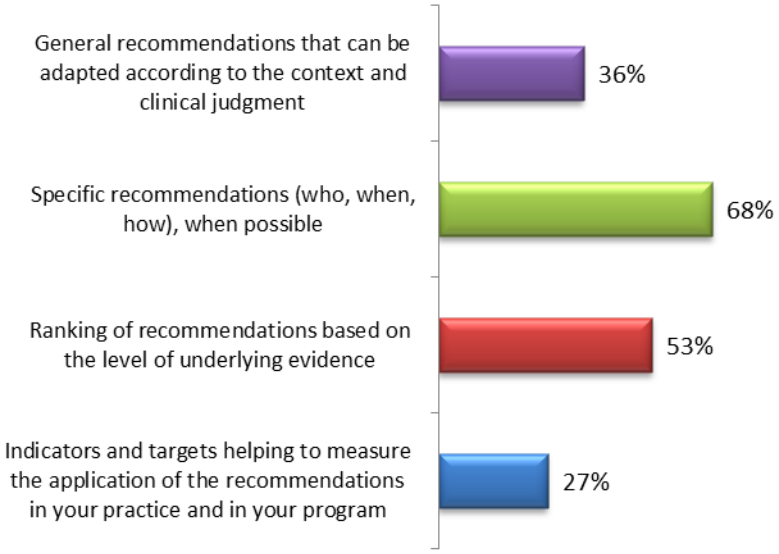
Why investigate this aspect so early? The development of a CPG requires a huge amount of time and resources. These efforts will be in vain if, in the end, the clinical settings do not adopt the tool and its recommendations, a pitfall that can result from the contents being suboptimally suited or from the materials or support for its use not being provided properly. Given this concern, the project team, in conjunction with its different partners in the health-care system, put in place mechanisms for planning and preparing the implementation phase. One of the pivotal steps in this preparation consists of documenting the expectations and preferences of the different intended users of the CPG in terms of the format and the facilitators and potential barriers to its implementation, knowing that these different elements may vary according to the province, occupational category and clinical setting.

What did the respondents say about these aspects? The respondents expressed a large preference for a CPG **in electronic format** (77% of the respondents), including **specific recommendations** (68%) and clearly indicating the **level of the evidence** on which they are based (53%). They reported the need for the recommendations to be easy to apply in clinical settings. The CPG should also be accompanied by several tools, such as treatment protocols, evaluation tools and checklists for recording interventions performed on the basis of the recommendations.

A few differences of interest

- The item concerning specific recommendations (who does what, when and how) was relatively less important to the ACF respondents (53% vs. 71% of the RIIU respondents and 74% of the RINIU respondents) but more important to the managers than the clinicians (86% vs. 65%, respectively).
- Similarly, more Ontario respondents (61%) than Québec respondents (49%) were in favour of prioritizing the recommendations according to the level of evidence.

Figure 10 - What form should the recommendations included in the CPG take (2 priority elements per respondent)

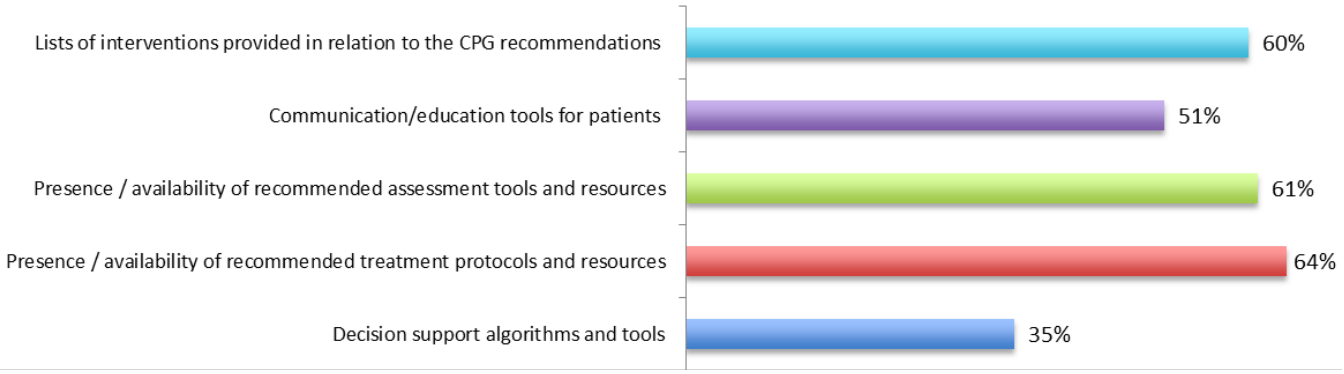


When asked about the complementary tools that should accompany the CPG, the respondents indicated, in order of priority, the treatment protocols in connection with the recommendations (64%), the recommended assessment tools (61%) and checklists for recording interventions performed on the basis of the recommendations (60%).

A few differences of interest

- Having treatment protocols seemed especially important to the RINIU respondents compared to the ACF respondents (73% vs. 40%, respectively).
- Although only 35% of all the respondents considered having decision algorithms a priority, we noted a considerable difference according to the occupational category, with 75% of the managers having identified them as a priority compared to 44% of the coordinators and 30% of the clinicians.

Figure 11 - Which complementary tools would most facilitate your use of the CPG? (3 priority elements per respondent)

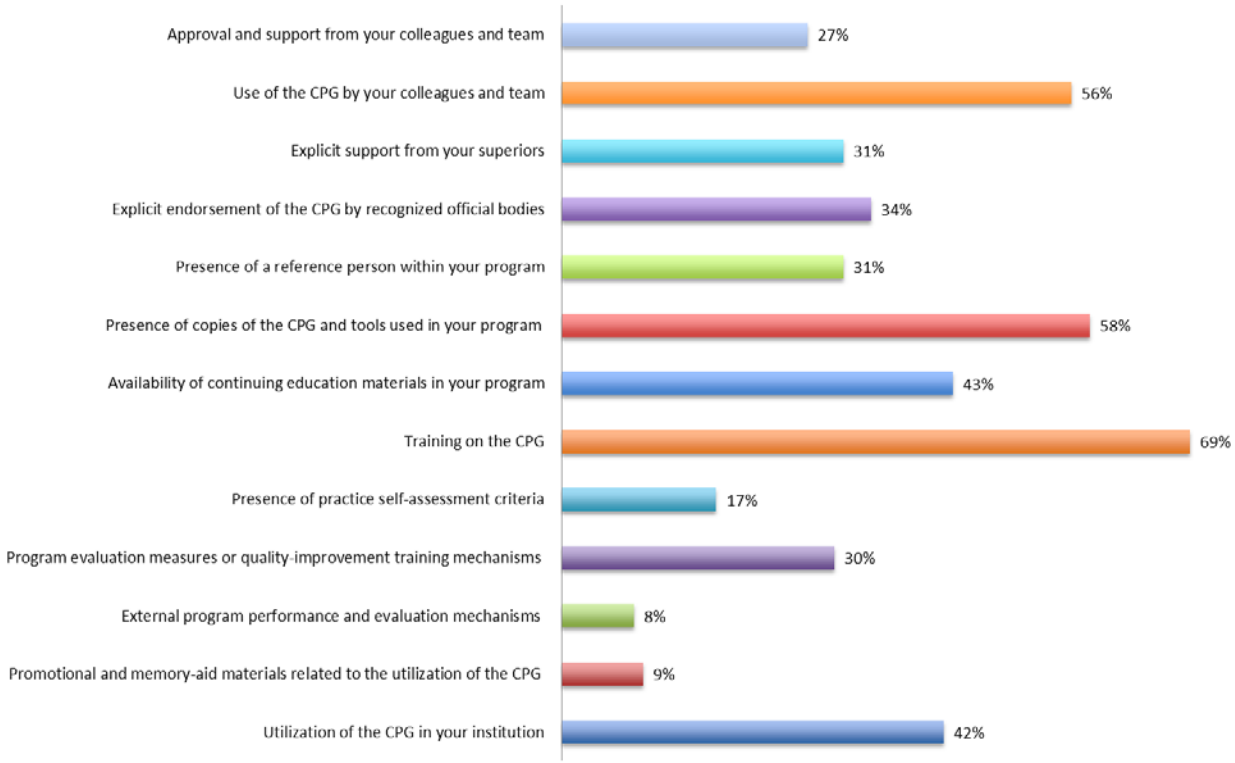


With regard to facilitators and barriers, the results of the consultation show that the elements that could facilitate the most the use of the CPG, according to the majority of the respondents, are the provision of training on the CPG (69% of the respondents), having easily accessible copies of the CPG in their clinical program (58%), and the use of the CPG by all of the team members (58%). The respondents indicated that the CPG must be usable in a rehabilitation context and they must have sufficient time to use it, otherwise, these factors could be major obstacles to the use of this resource .

A few differences of interest

- The shared use of the CPG by peers seems to be particularly important to the clinicians (60% vs. 36% of the managers).
- Although the overall response rate was lower for the presence of evaluation measures or formal continuous-improvement mechanisms, we observed that this element was considerably more important to the managers (46%) and program coordinators (44%) than to the clinicians (27%).
- In addition, 44% of the respondents indicated that the lack of explicit support from superiors could hamper the use of the CPG.

Figure 12 - Which element would most facilitate your use of the CPG in your daily practice? (5 priority elements per respondent)



On the whole, the respondents indicated that the proposed training should ideally include active learning strategies, such as clinical examples (76% of the respondents), interactive workshops (61%) and question periods (51%). Furthermore, many of the respondents mentioned the need for interdisciplinary training.

A few differences of interest

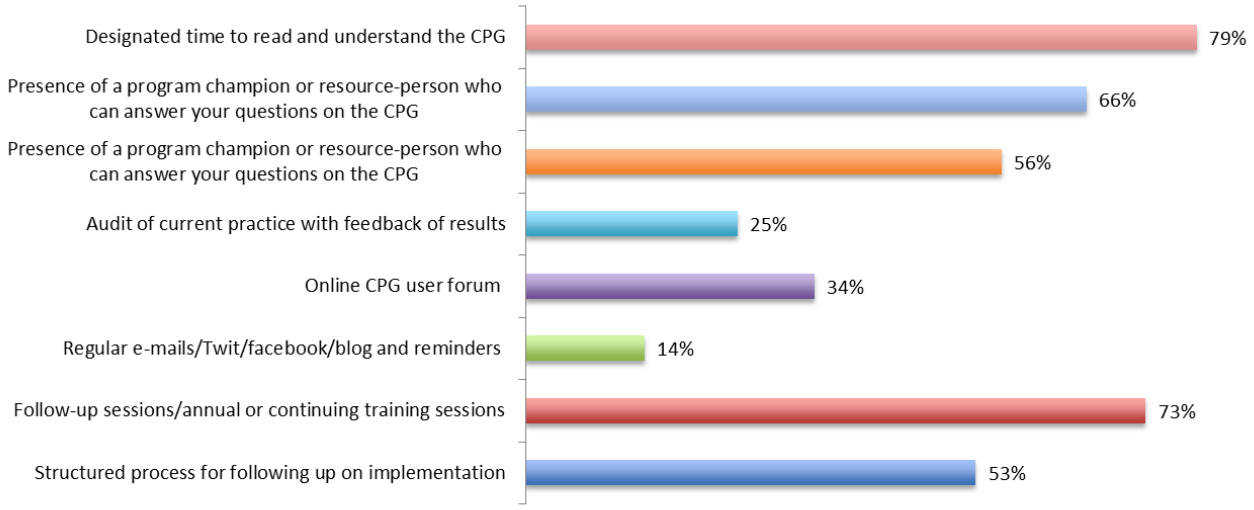
- A larger proportion of Québec respondents would prefer theoretical training on the CPG's contents (54% vs. 31%, respectively), while those in Ontario attached more importance to interactive workshops (70% vs. 56%, respectively).
- The ACF respondents attached greater importance to the availability of digital training tools than those in rehabilitation facilities (63% vs. 43% for the RIIU respondents and 42% for the RINIU respondents).
- In addition, a smaller proportion of the ACF respondents recommended question and discussion periods on CPGs (30% vs. 53% of the RIIU respondents and 60% of the RINIU respondents).

On the question of the strategy for the implementation process (see Figure 13), the results show that the respondents consider it important to have an authorized, designated period of time to read and understand the CPG (79% of the respondents), follow-up and ongoing training mechanisms (73%), the presence of a "champion" or resource person in the program (66%), mechanisms for analyzing gaps between routine practices and the recommendations (56%), and a relatively structured follow-up on the implementation process (53%).

A few differences of interest

- The time devoted to reading and learning the CPG was considerably more important to the Québec respondents (84%) than to those in Ontario (69%).
- An interprovincial difference was also observed with regard to the use of an audit and feedback process, which 37% of the Ontario respondents considered important compared to 19% of the Québec respondents.
- The presence of a «champion» or resource person in the program is strongly preferred by the managers (89%) and somewhat less so by the clinicians (62%).
- The managers also expressed greater interest (59%) in an online forum on the CPG compared to 29% of the coordinators and 32% of the clinicians.

Figure 13 - Other implementation methods and mechanisms which would most facilitate the implementation of the CPG in clinical practice (5 priority elements per respondent)



MAIN FINDINGS AND KEY MESSAGES

An analysis of the large body of comments and data obtained in this consultation enables us to make a few very interesting observations and provides important messages for continuing our work.

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More than half of the survey respondents were not aware of any CPGs dealing specifically with the rehabilitation of MSTBI patients, and a very small proportion of them used this type of tool in their practice. They expressed a rather favourable opinion of CPGs for supporting their professional activities, which confirms to us the need for and relevance of the project for developing and implementing a CPG for the rehabilitation of MSTBI patients.

The vast majority of the respondents identified the parameters of intervention intensity, frequency and duration, as well as models of care or reference frameworks, as being important elements to be covered in the CPG. **These concerns tie in directly with those of our "system" partners and decision-makers. Since we know there is less evidence concerning the intervention intensity, frequency and duration, the project team will probably have to turn to other types of information to address these issues**.

The topics pertaining to the intensive rehabilitation phase emerging as being the most important for future users of the CPG correspond fairly well to the most frequently affected and challenging dimensions following a MSTBI, namely, cognition, behaviours, energy level and sleep, as well as mental health. Although these topics were mentioned by all of the respondents, the order of priority across the subgroups differed. **Since a single, shared CPG will be produced, the project team will have to consider, in its implementation strategy, the possibility of modifying the order or priority of certain recommendations according to the needs and concerns of the various clinical and managerial teams.**

With regard to the social integration phase, we observed a **keen interest in matters concerning the expected or long term outcome(s) of the rehabilitation process of these patients**, namely, social participation and community life, skill maintenance and quality of life, the occupational sphere (work, school, etc.) and caregiver support. **The project team will have to take this more global perspective into account when organizing the more specific information making up the sections concerning social integration and social participation of people with MSTBI**.

A number of respondents provided comments or suggestions regarding other aspects they would like the CPG to cover, such as interventions for elderly patients. Although the project team has taken due note of these suggestions, the attention given to them in the CPG will always depend on the availability and quality of the evidence.

The information gathered about the CPG implementation process is helpful for facilitating the uptake and use of the CPG by managers, coordinators and clinicians in their clinical settings. **We have especially taken note of the expressed needs and expectations** regarding interdisciplinary and in particular, interactive training methods on the use of the CPG, the availability of evaluation and intervention tools, the presence of a resource person or «champion» for supporting the process, the possibility of granting time to read the guideline and to become familiar with its contents, easy access to the CPG and its tools, and a follow-up procedure to the implementation process. **As much as possible, the implementation strategy will try to incorporate these different mechanisms in order to optimize the adoption of the CPG and to ensure its sustained use.**

In closing, it is important to note that respondents were generally less favourable with regard to "measure" elements, i.e., indicators, external evaluation mechanisms (audits), self-assessment criteria, etc. Since the literature itself strongly supports these components in an implementation process and especially in a perspective of real, lasting practice changes, **the project team will have to adequately prepare and support the teams in endorsing and making constructive use of "measure" elements.**

NEXT STEPS

The information obtained through this consultation has been the subject of numerous discussions within the project's working committees in order to interpret the results adequately and derive the proper insights for continuing our work. Indeed, this material allows us to validate and adjust our goals in terms of the topics to be covered in the CPG, the tools to be developed, the topics that should be given priority, and the implementation mechanisms to be put in place. The next major step in moving this project forward consists of bringing together, in November 2014, the different scientific and clinical experts to select, refine and develop the recommendations and indicators that will constitute the bulk of the CPG. The team is presently working very hard at gathering and synthesizing all the data and available materials, which, of course, include the results of the user survey, in order to prepare for this important next step.

COMMENTS EXTRACTED FROM THE SURVEY

"It is important to share common practice and scripts, and embed good practice in standard care routines including electronic health records."

"This is a much needed project. Although my practice will still benefit tremendously, this would have been an invaluable resource five years ago when I began working with this client population and will be an important training tool for new rehab professionals entering this field."

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