Development and Implementation of a Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury in Québec and Ontario

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A inter provincial partnership

INESSS-ONF Guideline Development Team:

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Project coordinators

- **Ailene Kua, M.Sc (ONT) & Anne-Sophie Allaire, M.Sc (QC)**

+++ Collaborators
Aim of Presentation

To Introduce and Prepare for the Implementation of CPG’s for the Rehabilitation of Adults with Moderate to Severe TBI
Objectives

- Introduce the concept of clinical practice guidelines: why they are needed and who uses them

- Inform the audience about an ongoing partnership to adapt/develop and implement a Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury in Québec and Ontario

- Describe plans for implementing the guidelines and the potential barriers to implementation
What is a Guideline?

- What is evidence-based practice?
- Why are guidelines needed?
- Who uses guidelines?
Evidence Based Practice

• What is evidence based practice?

• The conscientious, explicit and judicious use of the current best evidence in making decisions about the care of individual patients. Sackett, 1996, BMJ 312, 71-72

• Clinicians who want to use EBP must find trusted and readily accessible sources for the best evidence, relevant to their practice area.
Clinical / Best Practice Guidelines (CPG’s)

- Systematically developed statements (based on best available evidence) to assist practitioner and patient decisions about appropriate health care for specific clinical (practice) circumstances. (Field & Lohr, 1990).

- “generated from a systematic, rigorous and explicit methodology, including a review of all available scientific literature under study.”
Clinical Practice Guidelines

- Systematically developed statements that help practitioners and patients identify and deliver appropriate health care

Scientific evidence
Clinical expertise
Patients’ opinions and preferences

Systematic production process

Clinical practice guidelines
Why Guidelines?

CPGs can:

• Identify the nature, volume and quality of research evidence supporting clinical recommendations
• Improve decision making and ultimately, clinical outcomes
• Improve consistency of care
• Inform patients and other stakeholders regarding the treatment they should be receiving
• Influence health policy to enhance treatment efficiency and access to services

How are Guidelines Developed?

- How are guidelines made?
  - Starts with the asking of a clinical question

- How is evidence turned into practice?

- Guideline Adaptation and Development Cycle (www.adapte.org)
Asking a Clinical Question

PICO
- P – patient/problem
- I – intervention
- C – Comparison
- O – Outcome

This method has been shown to improve retrieval of information
Hierarchy of Literature

- Clinical Practice Guideline (CPG)
- Systematic Reviews
- Meta-Analysis
- Randomized control trials
- Cohort studies
- Before and after studies
- Descriptive studies
- Consensus Exercises
- Care Maps
Evidence-based Medicine

- Systematic Reviews
  - Scientific investigations using pre-planned strategies
  - Includes all relevant articles, appraise primary trials and synthesize data.

- Meta-Analyses
  - Systematic reviews that use statistical methods
  - Combine primary trials
  - Produce a single pooled estimate of an intervention’s effect

- Clinical practice guidelines
  - "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances"

The Knowledge Translation Problem

‘All breakthrough, no follow through’

- The benefits of the US $100 billion/year worldwide investment in biomedical and health research are not optimally achieved because of knowledge translation failures
Knowledge to Action cycle suggests that planned process more likely to achieve practice changes.

The Knowledge Translation Problem

- Traditional KT approaches have emphasized publication in peer reviewed journals
- Consistent evidence of failure to translate research findings into clinical practice
  - 30-40% patients do not get treatments of proven effectiveness
  - 20–25% patients get care that is not needed or potentially harmful

Schuster, McGlynn, Brook (1998). *Milbank Memorial Quarterly*

Grol R (2001). *Med Care*
Question 1. I know of at least one clinical practice guideline (CPG) that supports the rehabilitation of adults with MSTBI.

1.1 Responses (n=371):

Question 2. I currently use at least one CPG to support the rehabilitation of adults with MSTBI

2.1 Responses (n = 357)

Median: 2
CLINICAL PRACTICE GUIDELINE
FOR THE REHABILITATION OF ADULTS WITH MODERATE TO SEVERE TBI
Need for adapted clinical practice guidelines (CPG) expressed by rehabilitation authorities

Expertise in Québec and Ontario (Canada)

Decision to start a new adaptation process to create clinical practice guidelines to guide the rehabilitation of adults with moderate to severe traumatic brain injuries
Our Project

The partnership between Institut national d’excellence en santé et en services sociaux (INESSS) and Ontario Neurotrauma Foundation (ONF) aims at structuring and facilitating the process surrounding the joint production of a clinical practice guideline (CPG) intended for clinicians and administrators delivering rehabilitation services to adults having sustained a moderate to severe TBI.
The steps of the project

1. Scoping review and quality evaluation of existing CPGs
2. Survey of end-users’ needs and expectations
3. Synthesis of all existing information
4. Expert consensus
5. Implementation of the CPG in the clinical settings
The scoping review

512 documents founds

Title and abstract screened

41 documents from grey literature

81 documents selected

17 analyzed in the scoping review

7 evaluated with AGREE-II

64 excluded

Figure 1. Flow-chart of the documents.
1. Guidelines Scoping Review

- Scoping review
- Quality evaluation
1. Guidelines Quality Evaluation

- Scoping review
- Quality evaluation

1. Guideline review

- Domain 1: Scope and purpose
- Domain 2: Stakeholder Involvement
- Domain 3: Rigour of Development
- Domain 4: Clarity and presentation
- Domain 5: Applicability
- Domain 6: Editorial Independence

Overall quality

I would recommend this guideline to use
The steps of the project

1. Scoping review and quality evaluation of existing CPGs
2. Survey of end-users’ needs and expectations
3. Synthesis of all existing information
4. Expert consensus
5. Implementation of the CPG in the clinical settings
2. The end-users consultation

- Electronic survey of 477 stakeholders in Québec and Ontario
  - From hospitals (22%), in-patient rehab facilities (51%) and out-patient rehab settings (21%)
  - Clinicians (73%), coordinators (8%) and managers (8%)
  - OT (18%), PT (16%), PSY (14%), Nurses (12%), SW (9%), Speech therapists (9%), MD (5%)
• **Four sections in the survey:**
  1) Profile of respondents
  2) Knowledge/perception of CPGs
  3) Content and format of CPG
  4) Implementation process

• **Target end-users:** All clinicians, physicians, clinical coordinators and managers of TBI programs in **acute care settings** and rehabilitation facilities in Quebec and Ontario.
2. Stakeholder consultation: Guidelines perceptions

- 47% of participants knew about at least one TBI CPG...
  - ...but they report as «very low» (mean: 3.5/10) the frequency of its use in their practice
- Participants have positive opinions about CPGs (mean: 7.6/10)...
  - ... but they feel moderately well equipped (5.7/10) to use the CPG in their practice
2. Stakeholder consultation: Guidelines topics

<table>
<thead>
<tr>
<th>Response</th>
<th>Chart</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access mechanisms</td>
<td></td>
<td>25%</td>
<td>78</td>
</tr>
<tr>
<td>Continuity-of-care mechanisms</td>
<td></td>
<td>59%</td>
<td>183</td>
</tr>
<tr>
<td>Coordination mechanisms</td>
<td></td>
<td>36%</td>
<td>111</td>
</tr>
<tr>
<td>Duration of interventions</td>
<td></td>
<td>66%</td>
<td>204</td>
</tr>
<tr>
<td>Length of stay</td>
<td></td>
<td>36%</td>
<td>113</td>
</tr>
<tr>
<td>Intensity / frequency of interventions</td>
<td></td>
<td>79%</td>
<td>246</td>
</tr>
<tr>
<td>Rehabilitation models or reference frameworks</td>
<td></td>
<td>74%</td>
<td>229</td>
</tr>
<tr>
<td>Program evaluation measures</td>
<td></td>
<td>44%</td>
<td>137</td>
</tr>
<tr>
<td><strong>Total Responses</strong></td>
<td></td>
<td><strong>310</strong></td>
<td></td>
</tr>
</tbody>
</table>
### Guidelines topics – early recovery

<table>
<thead>
<tr>
<th>Response</th>
<th>Chart</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence and prevalence of TBI and its associated conditions</td>
<td></td>
</tr>
<tr>
<td>General physical health</td>
<td></td>
</tr>
<tr>
<td>TBI-related conditions (e.g.: heterotopic ossification)</td>
<td></td>
</tr>
<tr>
<td>Epilepsy and other neurological disorders</td>
<td></td>
</tr>
<tr>
<td>Endocrine disorders</td>
<td></td>
</tr>
<tr>
<td>Vestibular and sensory impairments</td>
<td></td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td></td>
</tr>
<tr>
<td>Motor impairments</td>
<td></td>
</tr>
<tr>
<td>Cognitive function impairments</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td></td>
</tr>
<tr>
<td>Behaviour disorders</td>
<td></td>
</tr>
<tr>
<td>Orthotic devices and technical aids</td>
<td></td>
</tr>
<tr>
<td>Positioning and mobility</td>
<td></td>
</tr>
<tr>
<td>Pain management</td>
<td></td>
</tr>
<tr>
<td>Fatigue and sleep disturbances</td>
<td></td>
</tr>
<tr>
<td>Sexuality</td>
<td></td>
</tr>
<tr>
<td>Mental health (psychological and emotional conditions)</td>
<td></td>
</tr>
<tr>
<td>Pharmacological treatments</td>
<td></td>
</tr>
<tr>
<td>Substance abuse</td>
<td></td>
</tr>
<tr>
<td>Alternative medicine (e.g.: acupuncture)</td>
<td></td>
</tr>
<tr>
<td>TBI education</td>
<td></td>
</tr>
<tr>
<td>Vegetative state and individuals with low potential for recovery</td>
<td></td>
</tr>
</tbody>
</table>
### 2. Stakeholder consultation: Guidelines topics - later

<table>
<thead>
<tr>
<th>Response</th>
<th>Chart</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychosocial strategies</td>
<td></td>
<td>50%</td>
<td>151</td>
</tr>
<tr>
<td>Sport and physical activity</td>
<td></td>
<td>25%</td>
<td>76</td>
</tr>
<tr>
<td>Social participation and community life</td>
<td></td>
<td>68%</td>
<td>204</td>
</tr>
<tr>
<td>Leisure activities</td>
<td></td>
<td>29%</td>
<td>88</td>
</tr>
<tr>
<td>Caregiver support</td>
<td></td>
<td>57%</td>
<td>173</td>
</tr>
<tr>
<td>Skill maintenance and quality of life</td>
<td></td>
<td>62%</td>
<td>187</td>
</tr>
<tr>
<td>Activities of daily living</td>
<td></td>
<td>40%</td>
<td>122</td>
</tr>
<tr>
<td>Household activities</td>
<td></td>
<td>21%</td>
<td>62</td>
</tr>
<tr>
<td>Home adaptations</td>
<td></td>
<td>17%</td>
<td>52</td>
</tr>
<tr>
<td>Work, school and productivity</td>
<td></td>
<td>58%</td>
<td>176</td>
</tr>
<tr>
<td>Driving and travelling</td>
<td></td>
<td>32%</td>
<td>98</td>
</tr>
<tr>
<td>Responsibilities</td>
<td></td>
<td>23%</td>
<td>70</td>
</tr>
</tbody>
</table>

**Total Responses** 302
2. Stakeholder consultation:

They would like:

- Specific recommendations (who, when, how)
- Training (case histories, workshops, discussions), accessible CPG (electronic/paper copies) and team-use of the CPG (56%)
- Designated time to read and understand the CPG
- Program champion / resource person
- Follow-up (continual training)
The steps of the projects

(1) scoping review and quality evaluation of existing CPGs

(2) survey of end-users’ needs and expectations

(3) synthesis of all existing information

(4) expert consensus

(5) implementation of the CPG in the clinical settings
The steps of the projects

1. Scoping review and quality evaluation of existing CPGs
2. Survey of end-users’ needs and expectations
3. Synthesis of all existing information
4. Expert consensus
5. Implementation of the CPG in the clinical settings
The expert consensus panel

- Experts (n=60) consensus meeting to be held in November 2014, in Montréal (Québec)
- Formulate recommendations from scientific evidence
- Formulate indicators to allow for clinician performance measurement
Our project

Guideline Development and Adaptation

1. Review and evaluation of existing CPGs
   May – Nov. 2013

2. Validation of the end-users' needs and expectations

3. Synthesis of all existing documentation and evidence
   Mar. – Nov. 2014

4. Consensus process amongst experts
   Oct. – Nov. 2014

5. Adaptation of the recommendations and production of the guidelines
   Nov. 2014 – May 2015

Final Product

INESSS-ONF Guideline

Evaluation/Implementation: INESSS-ONF Guideline
May 2015 – May 2016

Presentations/Publications

Further input from panel experts
- Refinement
- Agreement
- External Review

INESSS-ONF Guideline: Final Product
Building Stakeholder Engagement: Making the Guidelines Relevant
Why is stakeholder engagement desirable?

- KT 101 - involve your user
- People can see themselves in the process
- Input on usability, feasibility of use
- Identifies barriers, confirms barriers and enablers
- Establish connections at several levels
  - Leadership, networks, professional associations, clinicians, consumers (patients)

- Managing expectations
- Leads to improved use and facilitates implementation
- Leads to improvements and standardization of care
Who are the stakeholders of guidelines?

- On the ground (end-users)
  - Clinicians – real life experience, managing expectations, make it feasible
  - Administrators – reality of policies and procedures, time management, implementation process
- Professional associations
  - Advocate, educate and communicate with members
  - New practitioners and long-term practitioners
  - Ongoing professional training
- Decision-makers
  - Networks – think more systematically, larger scope of feasibility and impact
  - Government – accountability, standards, cost, quality
- Patients and families – want to know they are receiving the best care
- Researchers
  - Especially those connected to the clinical settings - evidence of impact
Making guidelines relevant

• Formal endorsement of the development process (all levels)
• Identification of the needs, expectations, resistances
• Assessment of feasibility for implementation
• Engagement for uptake
• Patient engagement
• Broader stakeholders collaboration – government, agencies, professional associations
Structuring the process of engagement

INESSS-ONF Partnership:

- Professional networks as first-hand collaborators
- Governments as stakeholders
- Research outsourcing

- 10 acute care facilities
- 11 inpatient rehab facilities
- TBD outpatient rehab facilities
- 8 acute care facilities
- 9 inpatient rehab facilities
- 7 outpatient rehab facilities
Surveying end-users’ needs and expectations

ALLOWS US TO:

- Explore perceptions:
  - **actual level** of clinical rehabilitation practice and processes
  - CPGs (familiarity, acceptance, usefulness, actual use, projected usage)

- Identify needs regarding:
  - content of the CPG (domains, nature and format)
  - implementation of the CPG

- Facilitate the **mobilization** in the development, implementation and utilization of the CPG by:
  - Providing information on objectives and process underlying the project
  - Adjusting respective expectations and beliefs
  - Addressing potential obstacles and resistances
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Eligibility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eligible</td>
<td>477</td>
<td>95</td>
</tr>
<tr>
<td>Not eligible</td>
<td>23</td>
<td>5</td>
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<tr>
<td><strong>Institution location</strong></td>
<td></td>
<td></td>
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<tr>
<td>Quebec</td>
<td>251</td>
<td>56</td>
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<tr>
<td>Ontario</td>
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<td>44</td>
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<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>72</td>
<td>16</td>
</tr>
<tr>
<td><strong>Practice setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute hospital (early rehabilitation)</td>
<td>109</td>
<td>22</td>
</tr>
<tr>
<td>Rehabilitation institution with inpatient unit</td>
<td>256</td>
<td>53</td>
</tr>
<tr>
<td>Rehabilitation institution without an inpatient unit</td>
<td>120</td>
<td>25</td>
</tr>
<tr>
<td><strong>Current position</strong></td>
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<tr>
<td>Management position</td>
<td>37</td>
<td>8</td>
</tr>
<tr>
<td>Clinical coordinator position</td>
<td>45</td>
<td>10</td>
</tr>
<tr>
<td>Clinical position (including physicians)</td>
<td>389</td>
<td>83</td>
</tr>
<tr>
<td><strong>Field of professional training</strong></td>
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<td></td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>87</td>
<td>18</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>77</td>
<td>16</td>
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<td>Psychology</td>
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<td>7</td>
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<tr>
<td>Neuropsychology</td>
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<td>8</td>
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<tr>
<td>Social work</td>
<td>49</td>
<td>10</td>
</tr>
<tr>
<td>Speech therapy</td>
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<td>9</td>
</tr>
<tr>
<td>Nutrition</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Kinesiology/Physical education</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Special education</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>Recreation/Leisure therapy</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Nursing</td>
<td>59</td>
<td>12</td>
</tr>
<tr>
<td>Medicine</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>Administration</td>
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<td>2</td>
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<tr>
<td>Sexology</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Years of experience (years)</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Stakeholder communications

• Planned
• Continuous
• Transparent
• Engaging
• Informative
• Brief
• Adapted to audience
Sharing Survey Results

CLINICAL PRACTICE GUIDELINE FOR THE REHABILITATION OF ADULTS WITH MODERATE TO SEVERE TBI

THE LATEST NEWS

The project strives at developing a clinical practice guideline (CPG) for the rehabilitation of adults with moderate to severe traumatic brain injury (TBI) in progressing work. The following steps have been completed:

- Systematic review of existing practice guidelines.
- Evaluation of the content and quality of the existing CPGB.
- Creation of the Evidence Committee and Task Force (including an advisory subcommittee).
- Development of the evidence matrix and the preliminary statement for the CPG, with the aim to develop an evidence-based, national practice guideline.

The information gathered through this consultation will serve to ensure that the CPG development and implementation process is evidence-based.

We would like to thank everyone who participated in the initial consultation (phase 1) as this information is extremely helpful in developing the final version. The project team will be reviewing the next few months preparing for the final consultation and documentation tool, to be used to develop an expert recommendation using the advice and decisions made during this phase. As a result, stakeholders will be set up in the next few weeks in consultation with our various project partners. While this phase is taking place, the implementation strategy planning will continue.

For further information, you can contact the following at any time:

Catherine Chapman, catherine.chapman@geoff.org
Catherine Tuckman, catherine.tuckman@geoff.org
The perspective of people living with TBI

- Consumers (patient – family perspective)
- Not the users necessarily but the recipients
- Quality improvement – person centered care, patient satisfaction
- Guidelines require balance between
  - systemic (provincial/state) issues and organizational provision of care
  - individual wishes and needs of the broader consumer community
- Consumer associations represented on expert panels (OBIA, BIAC)
- Individual experts – consumer needs
  - INESSS-ONF
  - Endorsement of consumer associations
The steps of the project

1. Scoping review and quality evaluation of existing CPGs
2. Survey of end-users’ needs and expectations
3. Synthesis of all existing information
4. Expert consensus
5. Implementation of the CPG in the clinical settings
IMPLEMENTING OUR GUIDELINES
The implementation of the CPG

- Collaborative definition in progress
  - Clinicians, managers, policy makers
- Evidence-based implementation process
  - Strategy (ies), actors, timing, etc.
- Pilot projects in three settings
Implementation Tools

- Feedback and evaluation of guidelines
- Workshops
- Surveys
- Auditing
- Consensus conferences
- Other tools
An Implementation Strategy

Identification of key recommendations by panel of experts (post consensus conference)

Presentation of finalized CPG to main stakeholders (method + key recommendations + implementation strategy) Directors - managers - coordinators - ministry - health agencies

Designation of implementation champions in each facility

Selection by stakeholders of 2-3 mandatory recommendations + indicators to implement province-wide
- 1 in acute care facilities?
- 1-2 in rehab facilities?

Same-Diff?

Elaboration of implementation evaluation process Project team + Stakeholders

Train-the-Trainer workshop for implementation champions (presentation of CPG + method + selected recommendations + implementation process)

Implementation process in each facility

Gap analysis between recommendation and practice (NIRN tools?)
Adjustment of local implementation strategy
Training of ITI team by local Champion
Implementation of indicators
Practice change
Selection of additional optional site recommendations

Regular Champions meetings (with Project lead)
- Site reports
- Sharing of tools/strategies
- Preparation of implementation evaluation process

Evaluation of implementation process

Legend:
- Significant resources (training material / time / $$$) involvement by project team
- Significant resources (time / $$$) involvement by facilities

Site « readiness » prep.
Summary

- CPGs are important to evidence-based practice

- CPGs are being adapted to improve TBI rehabilitation in Ontario and Québec

- Clinical and consumer (as well as health authority) collaboration is needed to make the adaptation and implementation process successful