



---

**Interprofessional Consensus  
Meeting  
Cerebral Palsy and Hip  
Surveillance:  
Working towards creating  
a provincial standard**

***May 26-27, 2011  
Granville Island Hotel, Vancouver BC***

---

***Final – January 20, 2012***

---

ORGANIZED BY:  
Child Health BC  
4088 Cambie Street, Suite 305  
Vancouver BC, V5Z 2X8  
T: (604) 877 6410  
F: (604) 874 8702  
[www.childhealthbc.ca](http://www.childhealthbc.ca)  
[info@childhealthbc.ca](mailto:info@childhealthbc.ca)  
In Partnership with:  
The Neuromotor Program  
at Sunny Hill Health Centre for Children  
& Department of Orthopaedics  
at BC Children's Hospital

---



## Contents

<b>Executive Summary</b> .....	<b>3</b>
<b>About this Meeting</b> .....	<b>4</b>
<b>About this Report</b> .....	<b>4</b>
<b>The Case for Change</b> .....	<b>5</b>
Presentation 1: Providing Services for children with CP in BC .....	5
Presentation 2: Clinical Pathways - A route to evidence based standardized practice for children with CP....	6
Presentation 3: Issue Identification.....	6
Presentation 4: Surveillance: State of the Science – What are the details of international standards for hip surveillance?.....	7
Presentation 5: Intervention – State of the Science regarding Orthopaedic approaches .....	7
Presentation 6: Outcomes: How will we know if we have made a difference? .....	8
<b>Building Consensus in BC</b> .....	<b>8</b>
<b>British Columbia Consensus on Hip Surveillance in Children with Cerebral Palsy</b> .....	<b>10</b>
<b>Participant-Recommended Supports for Implementation</b> .....	<b>11</b>
<b>Next steps</b> .....	<b>14</b>
<b>REFERENCES</b> .....	<b>15</b>
<b>Appendix A: Discussion of Australian Standards of Care Guidelines</b> .....	<b>16</b>
<b>Appendix B: Discussion of Guidelines by GMFCS Level</b> .....	<b>23</b>
<b>Appendix C: Takeaway Tasks</b> .....	<b>27</b>
<b>Appendix D – Planning Committee and Attendees</b> .....	<b>28</b>

## Executive Summary

On May 26<sup>th</sup> and 27<sup>th</sup> 2011, a meeting was held in Vancouver, BC on the subject of hip surveillance guidelines for children with Cerebral Palsy (CP). The meeting was organized by Child Health BC; participants included orthopaedic surgeons, paediatricians, family physicians, therapists, and other healthcare practitioners and administrators involved in the care of children with CP.

Six presentations were given at the meeting, describing the population needs and describing best practices for early detection and intervention of hip dislocation of children with CP. The presentations established the need for:

- Improved hip displacement management through systematic surveillance and well timed intervention
- Province-wide standards and consistency of approach using tiers of service model
- Care coordination across multi-disciplinary and multi-agency teams
- Optimizing health care resources closer to home and strengthening community capacity

The objective and outcome of the conference was the development of a set of guidelines for CP hip surveillance in BC. *British Columbia Consensus on Hip Surveillance in Children with Cerebral Palsy* - developed after careful consideration of the Australian *Consensus Statement on Hip Surveillance for Children with Cerebral Palsy* and the current practice of surveillance in Sweden - are presented in the body of this report.

The group then looked at possible barriers to implementation and potential solutions to these barriers. Participants suggested:

- **Existing assets in each region could be leveraged for implementation**, including NICU follow-up, Child Development Centres, Sunny Hill Health Centre services, networks of physiotherapists, etc.
- A **registry could facilitate role clarity and communication** between health care providers
- A **multi-channel approach to educating and training health care professionals** for implementation of the guidelines.
- A **Cerebral Palsy (CP) Passport** to help both health care providers and families carry out guidelines.
- A practical, easy to adopt **approach to capture clinical examination results** for sharing among health care professionals.
- **Outreach to patients and families that address barriers of specific segments** (e.g. those in rural or Aboriginal communities, new immigrants)

The conference concluded with specific next steps:

1. Report summarizing consensus from this conference to be reviewed by Planning Committee and subsequently presented to the CHBC Steering Committee for sign-off.
2. Draft of system-wide implementation plan that specifically compares the list of barriers and solutions that was generated to the Australian and Swedish implementation plans to be reviewed by conference participants.
3. Follow-up meeting of participants of the May 2011 meeting, as well as health system planners.

## About this Meeting

Maureen O'Donnell, Executive Director of Child Health BC, opened the meeting by outlining the role of Child Health BC and meeting objectives.

### Role of Child Health BC

Child Health BC (CHBC), an initiative of the BC Children's Hospital, is a network of health authorities and healthcare providers dedicated to excellence in the care of infants, children, and youth in British Columbia. BC Children's Hospital is an agency of the Provincial Health Services Authority. Child Health BC's mandate is to bring together partners from BC's health authorities, The Ministry of Health, the Ministry of Children and Family Development, the Ministry of Education, and other provincial agencies and services to optimize the health of children and youth and to improve access to high quality clinical health services. In opening this conference, Dr. O'Donnell noted that the network also includes the BC Paediatric Society, the First Nations Health Council, and hopes to involve BC Medical Association in the future. This group is currently working together to create a vision for children's health services across the continuum from health promotion and prevention, to active services. The mission of CHBC is to build an integrated and accessible system of care for the purpose of improved health status and health outcomes for BC's children and youth.

CHBC organized this meeting as an opportunity to bring together the specific expertise of selected healthcare practitioners to generate a practice-ready BC model for state of the science hip surveillance for the children and youth with Cerebral Palsy (CP) throughout the province of BC. In attendance were physical therapists, occupational therapists, managers of therapy services, paediatric orthopaedic surgeons, paediatricians, developmental paediatricians, family doctors, radiologists, and representatives from government.

### Conference Objectives

1. To present an international consensus statement on hip surveillance standards, obtain stakeholder input and generate consensus/agreement regarding use in BC.
2. Using the standards as the basis for discussion, to identify barriers and supports for implementation. Discussion will include supports currently in place as well as barriers to standard implementation.
3. To consider the necessary evaluation of the system of service resulting from the guideline. What key evaluations questions should be considered? What tools are needed to answer those questions?

## About this Report

This report begins by describing the population need and case for hip surveillance in children with Cerebral Palsy (CP). Next, this report presents a draft consensus statement for hip surveillance for children with CP in BC as an important outcome of this meeting (see Objective 1). Discussion of existing international consensus statements is captured in Appendix A. The report continues by underscoring the importance of planning and evaluating care for this population in BC. In answer to the meeting's second objective, the report summarizes participant-recommended supports for implementation and closes with next steps following this conference.

## The Case for Change

Six presentations were given at the conference that established the case for change and challenged participants to think of streamlined and well-coordinated care across the continuum. These presentations are summarized in this section.

### Presentation 1: Providing Services for children with CP in BC

Summary of presentation by: **Janice Duivesteyn**, Program Manager, Neuromotor Program, Sunny Hill Health Centre for Children

CP is the most common cause of chronic physical disability in children. Its impact is lifelong and affects the child, parent/caregiver, family, healthcare system, and society in general. The prevalence of CP is estimated to be 2.6 per 1000 live births, which equals about 2600 children with CP in BC. Approximately 30% of the CP population are under the age of 6, and 70% are in the 6-19 range.

The importance of thinking more broadly about the children who receive services in BC was described by Ms. Duivesteyn, as there are implications in approaches across a range of needs: e.g. motor management, orthopaedics, positioning and mobility. The functional aspects include comfort, the ability to get around, and the ability to participate in social and community life. There are many broad needs for children with CP and these vary across severity level, age range, and personal/family context.

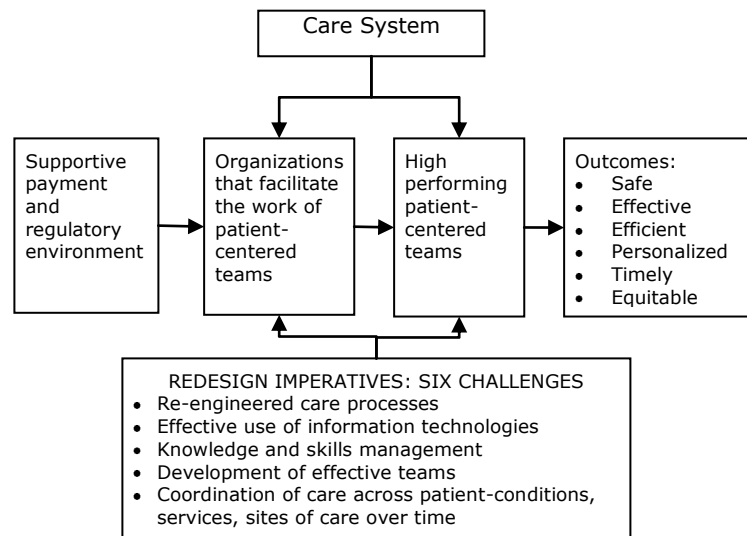
Ms. Duivesteyn drew attention to the importance of networks of collaboration across the tiers of service (see table below). Tier 3 and 4 services, in particular, play an important role in terms of providing consultation, education and training to regions so that services can be well developed and supported across all regions. In addition, Ms Duivesteyn encouraged consideration of existing networks such as professional councils and forums, common technologies (telehealth, videoconferencing), common indicators and guidelines and asked the audience to consider how these could be used to support the creation of a provincial standard for hip surveillance.

Tier	Types of services	Examples of resources
Tier 1	Broad-reaching services for children, including those with special needs	family physicians, public health, community services
Tier 2	Community special needs services	paediatricians, IDP, physiotherapist, early intervention, school-aged therapies
Tier 3	Regional, specialized services	regional orthopaedic surgeons, Queen Alexandra Centre
Tier 4	Provincial, sub-specialized services	Sunny Hill, BC Children's, GF Strong

## Presentation 2: Clinical Pathways - A route to evidence based standardized practice for children with CP

Summary of presentation by: **Dr. Esias Van Rensburg MD, FRCPC**, Medical Director, Neuromotor Program & Acute Rehabilitation Program, Sunny Hill Health Centre, BCCH

The rationale behind clinical care pathways was first outlined, along with the following diagram of how change can be made in the healthcare system to meet six quality dimensions of patient care. Dr. Van Rensburg gave an overview of four clinical pathways in existence or in development, all quite different in their approach. Dr. Van Rensburg then presented a diagram (*right*) that mapped out the functionalities and service modalities for children in each GMFCS level, providing an example of how a clinical care map might look.



With the implementation of electronic medical record with an information system/database, Dr. Van Rensburg suggested that there is an opportunity to reinvent our system of care for children with CP and their families. Organizing care and data capture may provide opportunity for research, as common clinical data, common documentation of treatments, and common outcome measures will exist.

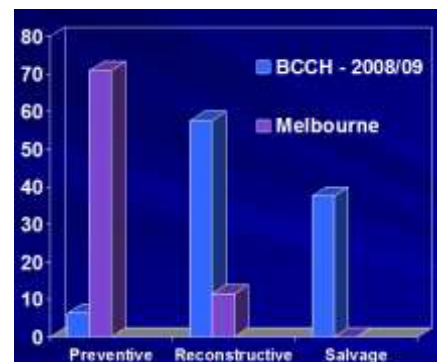
It was identified that a CP registry is being developed in BC, in collaboration with Dr. Shevell in Quebec. There is potential to develop a more comprehensive information system based on this.

## Presentation 3: Issue Identification

**Dr. Kishore Mulpuri MD**, Paediatric Orthopaedic Surgeon, BC Children's Hospital; Assistant Professor, Department of Orthopaedics, University of BC

Hip displacement and dislocation is the second most common musculoskeletal deformity affecting children with cerebral palsy after equinus. In three population studies, the rate of hip displacement was found to be one-third (35%,27%,32%). Dislocation of the hip in cerebral palsy results in significant morbidity. The consequences of hip displacement include pain, limited range of motion, problems with sitting, inefficient or loss of gait, difficulty with hygiene and personal care, pelvic obliquity and scoliosis, fractures, and skin ulceration.

At Children's Hospital, out of 13-14,000 clinic visits per year, 2000 are children with CP. In the past, there has been no allocated PT, OT, or RN support for children with CP in Orthopaedics. When compared nationally, BCCH had the most under-resourced orthopaedic clinic in the country. Compared with Australia, BC has more surgeons treating children with CP but less support.



Dr. Mulpuri described how BCCH was doing a great deal of salvage surgery for painful hip dislocations while in Melbourne, during the same period, more preventive surgeries were being done (recognizing that it was probably early intervention as there is no 'preventive' *per se* in CP). A large number of children and youth with CP were placed on the surgery wait list in BC, which put a strain on resources and OR time and resulted in long wait times. Patients were getting worse while on wait list, which led to complaints to the Provincial Quality Care office. A gap analysis was completed and a business case made to the hospital administration; this is what brought the group together for this meeting.

## Presentation 4: Surveillance: State of the Science – What are the details of international standards for hip surveillance?

Summary of presentation by: **Ms. Stacey Miller**, *Physiotherapist, Orthopaedic Cerebral Palsy Clinic, BC Children's Hospital*

Hip surveillance is the process of identifying and monitoring the critical early indicators of progressive hip displacement by an active screening program. The premise of surveillance is that early detection (e.g. of hip subluxation) leads to early intervention, thus reducing the need for reconstructive surgery, and reducing or eliminating salvage surgery (and increased morbidity and health related costs).

The CPUP program in **Sweden** is a registry and healthcare system for children with CP that began in 1994 and went national in 2005. Its main goal is the prevention of hip dislocation and severe contractures. Standardized assessments are performed by PTs and OTs, and standard radiographs of the hip and spine are performed at different ages and frequency depending on [Gross Motor Function Classification System](#) (GMFCS) level. Reports are compiled via the internet to show the child's development over time. Because of this, deterioration in gross or fine motor function, ROM, hip displacement, and scoliosis can be detected at an early stage. Prior to CPUP, there was a 10% hip dislocation rate, compared to a present 0% rate. The CPUP program has also reduced the number of severe contractures, windswept deformity, and severe scoliosis.

Ms. Miller then presented details from the **Australian guidelines** on the clinical assessment, musculoskeletal examination, and radiological examination, as well as specifications for migration percentage and standardized positioning. In three population studies, the risk of hip displacement (defined by migration percentage) was shown to be directly related to child's GMFCS level, and not related to type of movement disorder. Accordingly, guidelines for each GMFCS level (as well as Winters, Gage and Hicks Hemiplegia Group IV) specify surveillance methods and frequency, and show when the children should be referred to orthopaedic surgeons.

## Presentation 5: Intervention – State of the Science regarding Orthopaedic approaches

Summary of presentations by: **Dr. Kishore Mulpuri MD**, *Paediatric Orthopaedic Surgeon, BC Children's Hospital; Assistant Professor, Department of Orthopaedics, University of BC*

Dr. Mulpuri provided an overview of surgical and non-surgical interventions for hip displacement and dislocation. He made the assertion that "standardizing surveillance is useful only if it leads to a systematic approach to what you do with those results."

Hip dislocation is preventable through early identification and intervention (Dr. Mulpuri clarified that although dislocation can be prevented, displacement generally cannot). Early diagnosis and prompt surgical treatment minimize the extent of further surgery. Treatment strategies depend on the extent of hip displacement noted, secondary bony changes, pain, age, and the child and family.

Dr. Mulpuri then reviewed treatment strategies based on the extent of hip displacement. These included Botox injection, soft tissue release, a combination of soft tissue release and bony reconstruction, and soft tissue and salvage surgery.

## Presentation 6: Outcomes: How will we know if we have made a difference?

Summary of presentation by: **Dr. Unni Narayanan** MBBS, MSc, FRCSC, Associate Professor, Department of Surgery, Hospital for Sick Children, University of Toronto; Scientist, Bloorview Research Institute

Understanding the consequences of hip instability tells us what our goals for treatment are. Surveillance is predicated on the assumption that it will lead to early detection, which then leads to early interventions and that our interventions are effective, safe, timely, and cost-effective.

Dr. Narayanan described how management goals are different for ambulatory and non-ambulatory children. For the latter, the goals of interventions are comfort, facilitation of care giving, and preserving or improving health in general and quality of life. For ambulatory children with CP, the goals are to prevent future arthritis and pain, to improve gait efficiency, and to increase activity and participation.

However, the things we measure are often the things we *can* measure — spasticity, range of motion, and radiographs — as opposed to the ultimate purpose of interventions. Dr. Narayanan looked at the need to be able to measure Quality of Life (QOL) in order to evaluate the effectiveness of treatments, and gave an overview of the measure he and his team developed and ongoing development of other relevant instruments.

Based on interviews with caregivers, surveys of health professionals, and reviews of other instruments, a team at Sick Kids developed and validated a 37-item set of measures. The [CPCHILD](#)® (Caregiver Priorities and Child Health Index of Life with Disabilities) questionnaire has six domains: (1) personal care and activities of daily living; (2) positioning, (3) transferring and mobility; (4) comfort, emotions and behaviour; (5) communication and social interaction; health; and (6) quality of life. A seventh section asks caregivers to rate the importance of each item's contribution to their child's overall quality of life.

To determine if hip reconstruction is helping children with severe CP, the team undertook an observational prospective cohort study comparing children who had hip reconstructive surgery for hip instability with those who had similar pathology but had not undergone surgery. Baseline CPCHILD scores were almost identical. Preliminary results show that CPCHILD total and domain scores improved significantly in the operated group while the CPCHILD scores remained stable or deteriorated in the control group over 12 months. Further research on hip interventions is planned as part of the **Scope Project**, an international, multi-centre study looking at longitudinal cohort studies and trials in fifteen centres in five countries.

The team at Sick Kids is working on a new set of measures for ambulatory children with CP — [GOAL \(Gait Outcomes Assessment List\)](#) — that will focus on the patient's goals for the intervention. The list includes 48 items across six domains: ADL and independence, gait function and mobility, comfort and endurance, sports and recreation, and body image/self-esteem.

## Building Consensus in BC

The group then discussed the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care (Wynter et al., 2008a; Wynter et al., 2008b), looking specifically whether these could be implemented in BC, or whether changes were needed. Comparison was made with surveillance guidelines used in Sweden (Hagglund et al, 2007).



Discussion also included the purpose of surveillance, delineation of roles and responsibilities, and lack of evidence. The following section summarizes where the group came to consensus regarding hip surveillance in BC. Full details of the discussion are provided in “Appendix A: Discussion of Australian Standards of Care Guidelines”

Consensus among the group was reached on the following:

- **Surveillance needs to be standardized**
- **GMFCS levels should be used as the basis for surveillance**
- **The definition and description of hip surveillance as described in the Annotations and References for the Annotations and References for the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care (Wynter et al., 2008b) will be adopted**
- **The definition of CP published by the NIH consensus group is most appropriate for the BC guidelines.**  
Cerebral palsy is “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum, et al., 2007, p. 9).
- **The definition and description of progressive hip displacement, dislocation and sequelae as described in the Annotations and References for the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care (Wynter et al., 2008b) will be adopted**
- **One radiograph, an AP of the pelvis, is sufficient for surveillance**
- **Closure of the triradiate cartilage will be used to indicate skeletal maturity**
- **Migration percentage of 30% should be the trigger for being flagged as at-risk**
- **The guidelines are not looking at interventions**

There was discussion regarding which measures should be included as part of the clinical examination of the hip surveillance program. The lack of evidence, need to standardize assessments, and indicators for a referral to an orthopaedic surgeon were reviewed. At the conclusion of the discussion, the clinical exam included the measures and indicators listed below. However, it was noted that a subgroup may be needed to review musculoskeletal measures to see if the list can be shortened. It was also discussed that overall guidelines for referrals to orthopaedic surgeons still need to be worked on.

Clinical Examination:

- GMFCS Level / Gait pattern
  - Hip abduction
  - R1/R2 (Tardieu)
- Thomas test
- IR/ER
- Care and comfort
- Pain
- Spine / pelvic obliquity
- Leg length

There was agreement to remove the Modified Ashworth test from the list used by the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care (Wynters et al., 2008b).

The group then discussed specific guidelines for each of the GMFCS levels. The agreed-upon BC guidelines are presented in Section 3: British Columbia Consensus on Guidelines for Hip Surveillance In Children with Cerebral Palsy. Full details of the discussion are provided in Appendix B: Discussion of Guidelines by GMFCS Level.

## British Columbia Consensus on Hip Surveillance in Children with Cerebral Palsy

### Recommended Frequency of Hip Surveillance

#### GMFCS I & II

- At each assessment, verify GMFCS level and identify children as hemiplegia WGH IV; if GMFCS level has changed or child identified as having Type IV hemiplegia, ongoing surveillance according to confirmed classification
- Initial clinical assessment at identification
- Review annually with clinical assessment
- Review at 6 years of age with clinical assessment and AP pelvic x-ray
- If x-ray findings are normal at 6 years, discharge from surveillance

#### Hemiplegia Type IV

- Surveillance as per guidelines for GMFCS I & II up to 6 years of age
- After 6 years of age, until skeletal maturity, review with:
  - Clinical assessment 12 monthly
  - AP pelvic x-rays 12 monthly

#### GMFCS Level III

- At each assessment, verify GMFCS level; if GMFCS level has changed, ongoing surveillance according to confirmed classification
- Initial clinical assessment at identification
- Clinical assessment and initial AP pelvic x-ray at 24 months of age
- Clinical assessment and AP pelvic x-ray 12 monthly until 6 years of age
- After 6 years of age, until skeletal maturity, review with:
  - Clinical assessment 12 monthly
  - AP pelvic x-rays 24 monthly

#### GMFCS IV & V

- At each assessment, verify GMFCS level; if GMFCS level has changed, ongoing surveillance according to confirmed classification
- Initial clinical assessment at identification
- Clinical assessment and initial AP x-ray at 24 months of age
- Clinical assessment and AP pelvic x-ray 6 monthly until 6 years of age
- After 6 years of age, until skeletal maturity, review with:
  - Clinical assessment 12 monthly
  - AP pelvic x-rays 12 monthly

## Participant-Recommended Supports for Implementation

The group divided into smaller groups, by geographic region, to discuss barriers to implementation. The main areas of discussion were providers, child & family, system organization, physical resources and supplies, and information. Participants discussed that the purpose is to respond to a clinical problem in BC, so provincial roll-out should start with levels III, IV and IV as this will catch children most at risk for hip dislocation. The groups then discussed possible solutions to the barriers, from a regional perspective.

Potential Barriers to Implementation	Suggested Supports
<p><b>Potential Challenge:</b> Engaging the Right Health Care Providers</p> <ul style="list-style-type: none"> <li>▪ <b>Inadequate supply of health human resources</b> (including turnover and hard to fill PT vacancies)               <ul style="list-style-type: none"> <li>• Rural areas do not have a physiotherapist, paediatrician, or even a GP</li> </ul> </li> <li>▪ Need to ensure that under-resourced areas and populations have adequate resources for physiotherapists to complete surveillance. Examples:               <ul style="list-style-type: none"> <li>• Physiotherapists in school districts (already under-resourced)</li> <li>• Sole charge therapists</li> <li>• Physiotherapists in aboriginal communities</li> </ul> </li> <li>▪ Many kids have early intervention services (birth to 5) but not transitioned into school-age programs so might be lost</li> <li>▪ <b>Cost of health human resources</b> needed to implement (physiotherapists outside of health authority, radiology resources, etc.); who will fund?</li> <li>▪ Disparity in funding for CDCs</li> <li>▪ Varying access to Tier 3 services</li> </ul>	<p><b>Suggested Support: Leverage Existing Assets in Each Region</b></p> <p><u>Provincial</u></p> <ul style="list-style-type: none"> <li>▪ <b>Neonatal follow-up</b> program captures many of these children; may collaborate</li> <li>▪ <b>Child Development Centres (CDC)</b> can play a central role in disseminating info in some regions               <ul style="list-style-type: none"> <li>• Could school-age therapy children (GMFCS III-IV) come back to CDC annually for hip screening</li> <li>• Some CDCs have a paediatrician who could sign x-ray requisitions, but not all do</li> <li>• If CDC PT departments take on primary role, and get from <b>BCCH</b> some signed x-ray requisitions, could facilitate handing these out.</li> </ul> </li> <li>▪ <b>Use telehealth</b> not only for education but also as evaluation tool</li> <li>▪ Link with <b>other screening programs</b>, e.g. hearing impairment, mammography – what can we learn from them</li> </ul> <p><u>Vancouver Island</u></p> <ul style="list-style-type: none"> <li>▪ Have good network between therapists</li> <li>▪ Therapist can be the person organizing the surveillance</li> <li>▪ Therapist would send out form to GP to order x-ray; or use a stamp so orthopaedic surgeon orders x-rays</li> <li>▪ Copy to one person reading all the x-rays</li> </ul> <p><u>Lower Mainland</u></p> <ul style="list-style-type: none"> <li>▪ Access to Sunny Hill's services</li> </ul> <p><u>Fraser</u></p> <ul style="list-style-type: none"> <li>▪ CDC central</li> </ul>

Potential Barriers to Implementation	Suggested Supports
<p><b>Potential Challenge:</b> Engaging the Right Health Care Providers (Continued)</p>	<p><b>North</b> (<i>size of all other regions combined, so approach has to be individualized</i>)</p> <ul style="list-style-type: none"> <li>▪ GP-driven, with physiotherapy assessments and close communication between caregivers. Paediatricians should also be closely involved</li> <li>▪ In medium-sized towns, have one GP see all the kids under hip assessment (would be easier to manage; less chance of error) <ul style="list-style-type: none"> <li>▪ Interior - smaller towns - probably still GP driven</li> <li>▪ Prince George - centralized, but GPs involved so they understand what we're doing</li> </ul> </li> </ul>
<p><b>Potential Barrier:</b> Lack of role clarity between health care professionals (GP/FPs, physiotherapist, etc and gaps between service tiers)</p> <ul style="list-style-type: none"> <li>▪ Need clarification on flow of service</li> <li>▪ Communication between barriers</li> <li>▪ Who will read the x-rays? consistent/different from region to region?</li> <li>▪ Who makes sure the x-rays are done?</li> <li>▪ Who will take the responsibility if people don't come in for surveillance?</li> <li>▪ Who does what if an x-ray comes back as abnormal?</li> <li>▪ Concern re: lack of care coordination, continuity of care and transfer of care</li> </ul>	<p><b>Suggested Support: Invest in Feasible Way to Capture Clinical Examination</b></p> <ul style="list-style-type: none"> <li>▪ Have a checklist or standardized form; simplified mechanism of capturing this info</li> <li>▪ Simplify so that it's reliable and do-able, as opposed to an exhaustive list that doesn't get done because people have no time or don't feel equipped to do it Learn from how Australia and Sweden have packaged these in a way accessible to therapists in their communities</li> </ul>
<p><b>Potential Barrier:</b> Current Information Management</p> <ul style="list-style-type: none"> <li>▪ Inter-operability of and/or dual entry of data: (e.g. Physiotherapists typing into two charts)</li> <li>▪ Cost of registry development and good implementation throughout the province</li> <li>▪ Responsibility for registry governance, records storage and access for caregivers, outcomes analysis</li> <li>▪ Unresolved issues with patient and provider identification in many healthcare records</li> <li>▪ Access model for Provincial Diagnostic Imaging Viewer does not take into account anyone outside the healthcare authorities</li> <li>▪ In some communities, imaging is not digital (although the</li> </ul>	<p><b>Suggested Support: Develop Registry</b></p> <ul style="list-style-type: none"> <li>▪ Registry could address multiple barriers: what are the provider roles; communication between them; rural regions specify who the primary care provider is list of all the people involved with the child: paediatrician, physiotherapist, GP, etc.</li> </ul> <p><b>Suggested Support: Communication Strategies</b></p> <p>Standardize reporting structure, per mammography model Clearly indicate routine screening vs. referral to an orthopaedic surgeon in report from physical exam - same with x-ray result Ensure x-rays come back to CDC rather than going to GP only Send reminders sent to all the people on the list</p>

Potential Barriers to Implementation	Suggested Supports
<p>majority now scanning their films)</p> <p><b>Potential Barrier: Knowledge and training gaps for health human resources</b></p> <ul style="list-style-type: none"> <li>▪ Familiarity of primary care providers with GMFCS on which guidelines are based?</li> <li>▪ Training of new providers in paediatric neuromuscular</li> <li>▪ Differences in x-ray technique and consistency of positioning</li> <li>▪ Who will complete continuing education for new health care providers</li> </ul>	<p><b>Suggested Support: Develop Health Care Professional Education and Training</b></p> <ul style="list-style-type: none"> <li>▪ Include what the program is about, how it works, even how to do certain assessments - online videos for range of motion testing, x-ray positioning</li> <li>▪ Use telehealth for educating a whole group of people in outlying areas and prevent travel as much as possible - successful in northern Ontario</li> <li>▪ Outreach to four types of health care professionals through established channels               <ol style="list-style-type: none"> <li>1. GPs through BCMA</li> <li>2. Physiotherapists through their network</li> <li>3. Paediatricians through paediatric societies in some regions</li> <li>4. X-ray technicians through therapists attending X-ray to help with positioning</li> </ol> </li> <li>▪ Provide Child with CP Passport</li> <li>▪ Information/educational/clinical piece could be combined into one document</li> <li>▪ Passport would have all the protocols, etc.</li> <li>▪ Similar copy kept at head office</li> <li>▪ If a surveillance piece isn't done at CDC, then someone else could pick up</li> </ul>
<p><b>Potential Barriers: Child and Family Access to Care</b></p> <p>Family access to all resources is variable depending on:</p> <ul style="list-style-type: none"> <li>▪ Family knowledge and education</li> <li>▪ Distances and weather conditions</li> <li>▪ May access services in another region (e.g Northeast children treated in Edmonton)</li> <li>▪ Psychosocial adversity</li> </ul> <p>The following families have challenges:</p> <ul style="list-style-type: none"> <li>▪ Immigrants with poverty, lack of family support, ESL</li> <li>▪ <b>Aboriginal</b></li> <li>▪ <b>Transient</b> families</li> <li>▪ <b>Multiple caregivers</b> (E.g. Children in MCFD care)</li> <li>▪ Families with <b>trust issues</b> with the healthcare community;</li> <li>▪ Those who make alternative healthcare choices</li> </ul>	<p><b>Suggested Supports:</b></p> <ul style="list-style-type: none"> <li>▪ Younger children are hopefully in early intervention physiotherapy; seeing them with the family (as opposed to in school) facilitates communication with the family</li> <li>▪ Consider CYSN framework to address the access barriers in BC</li> <li>▪ Develop education videos for families</li> <li>▪ CP Passport helps inform families about program</li> <li>▪ Translate materials into other languages and/or subtitled</li> <li>▪ Use telehealth to prevent travel as much as possible - successful in northern Ontario</li> <li>▪ Target walk-in clinics to reach out to immigrant families</li> </ul>

## Next steps

The process for the steps following the meeting was then outlined by Maureen O'Donnell.

### **1. Summary document**

A summary document will be prepared and will be reviewed by Planning Committee. The document will be taken to the CHBC Steering Committee for sign-off.

### **2. System-Wide Implementation Plan**

A system-wide plan for implementation will be drafted. The list of barriers and solutions generated in this conference will be specifically compared to the Australian and Swedish implementation plans. The draft implementation plan will then be brought back to the group, or a sub-group, for additional input; at the point of looking at a specific, pragmatic view of how this will work, more health planners will be brought in (managers, funders, those with clinical expertise).

### **3. Next Meeting**

The group will then be invited to meet again; the second draft implementation plan will be circulated before this meeting. The meeting can be virtual (via telehealth, videoconference, or web conference), or it can be a series of in-person meetings, or it can be a two-day meeting similar to this one. (The group was in favour of the latter).

### **4. Immediate Tasks**

Several takeaway tasks that will inform the guidelines and implementation plan are listed at the end of Appendix A. Members of the group were asked to also think about what things can happen now, particularly in terms of education, as this can commence before the full systematic plan is in place.

## REFERENCES

Hagglund G, Lauge-Pedersen H, Wagner P. (2007). Characteristics of children with hip displacement in cerebral palsy. *BMC Musculoskeletal Disorders*, 8, 101.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2007). A report: The definition and classification of cerebral palsy April 2006. *Dev Med Child Neuro*, 49(2), 8-14.

Wynter, M., Gibson, N., Kentish, M., Love, S.C., Thomason, P. & Graham, H.K. (2008a). Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care 2008.

[http://www.ausacpdm.org.au/\\_data/assets/pdf\\_file/0007/14569/consensus\\_statement.pdf](http://www.ausacpdm.org.au/_data/assets/pdf_file/0007/14569/consensus_statement.pdf)

Wynter, M., Gibson, N., Kentish, M., Love, S.C., Thomason, P. & Graham, H.K. (2008b.) Annotations and References for the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care 2008.

[http://www.ausacpdm.org.au/\\_data/assets/pdf\\_file/0019/14554/annotations\\_refs.pdf](http://www.ausacpdm.org.au/_data/assets/pdf_file/0019/14554/annotations_refs.pdf)

## Appendix A: Discussion of Australian Standards of Care Guidelines

**Australia** has had hip surveillance in all states since 1997. The primary aim is to provide a comprehensive system for early detection and management of spastic hip displacement and to educate parents, carers, and referring agencies. The principal effects on surgical practice were that more preventive surgery was carried out at a younger age and a more appropriate stage of the disease; the need for reconstructive surgery decreased; and salvage surgery was eliminated. Successful implementation is in large part due to a coordinated approach between orthopaedic surgeons and PTs.

The Australian Standards of Care guidelines were developed using published evidence, and augmented by expert opinion where published evidence was not available. The guidelines are based on GMFCS level. Clinical and radiological examination are required as part of surveillance (except GMFCS I), and frequency of surveillance is dependent on GMFCS level.

Conference participants discussed the Australian guidelines, looking specifically whether these could be implemented in BC, or whether changes were needed. Comparison was made to guidelines used in Sweden. Larger issues related to the purpose of surveillance, delineation of roles and responsibilities, and lack of evidence were discussed and are summarized here. The *Annotations and References for the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care, 2008, Document 2 of 3* were discussed in detail; the discussion points are outlined in this section. Appendix B: Discussion of Guidelines by GMFCS Level gives discussion topics specifically related to the contents of the guidelines.

### Key Points and Questions

- ❖ It is important to note that the purpose of the hip surveillance is to identify the children at risk, and not to prescribe treatment or standardize for the purpose of research.
- ❖ Screening programs are good when we know for sure we have an intervention that makes a difference. Screening for the sake of screening isn't of any value.
- ❖ When looking at interventions, it is important to remember that the GMFCS I, II and IIIs are very different from the IVs and Vs, because we have different goals for each.
- ❖ We want the science right on collecting what we need: necessary information vs. helpful information vs. information gathered for research.
- ❖ We are trying to make evidence-based decisions, but currently there is a lack of evidence on treatments. It is important to remember that the Australian guidelines are not based on evidence but on consensus.
- ❖ Who will do the surveillance? Is this an implementation issue or does it relate to defining surveillance? Is the purpose of surveillance to alert the primary care provider, the physiotherapist, the family doctor, or the paediatrician? Or is it a secondary level of surveillance that sends the child to a paediatric surgeon?
- ❖ In advocating the introduction of a new health intervention, three questions have to be asked:
  1. Can it work? – in a particular region, it can
  2. Will it work? – what about in another region?
  3. Is it worth it? – if this put into motion, it can take a lot of time and expense

### Definitions

The group discussed the definition of **surveillance** versus **screening**. Terminology was deemed to be important, and the following suggestions made:

Screening is universal; surveillance is for those that the screening process identifies as at-risk.

There is selective screening of those deemed to be at greater risk, based on GMFCS level and age, to generate the first consultation with an orthopaedic surgeon.



The point of surveillance is that it prompts the correct next step; once a problem is identified, the patient is no longer in surveillance mode but evaluation mode.

Surveillance is something done over time; the screen is the actual tool used — e.g. an x-ray — that is part of the surveillance system.

Consensus was not reached on these terms.

## Evidence for Intervention

There is a lack of evidence regarding the interventions provided, although there is a growing, lower-level quality of evidence that we can make a difference if interventions occur earlier. In moving forward with hip surveillance program, a commitment is needed to standardize intervention programs so that those involved can contribute to this body of evidence. However, that would be a separate meeting.

First, agreement is needed on what interventions will be done in BC; once these are more standardized, they can be compared with other centres. This meeting should take place again in a few years based on new and better evidence.

## Surveillance vs. Research vs. Care

The Australian guidelines, besides providing surveillance protocols, are also aimed at facilitating research. In creating the BC guidelines, it is necessary to consider what is practical for clinical practice versus what is desirable for research.

Surveillance must also be separated from decision-making for treatments.

## Roles and Responsibilities

Who does what, in terms of surveillance: the GP, paediatrician, orthopaedic surgeon, physiotherapist?

Does the child have a physiotherapist and/or a GP?

Who is reading the x-rays?

### Who performs the clinical exam, and who refers the children?

Who is seeing the children, and who will pick up the hip at risk?

Ideally a physiotherapist would do the assessments; however, they cannot order x-rays. X-ray information does not always come back to the physiotherapist. The therapists need to know whether the hips are completely in, as this affects not only the treatment but the communication strategies with the surgeons.

The surveillance program must be simple, short, and efficient, otherwise doctors will delegate it to someone else.

Is surveillance done by the GP in conjunction with the physiotherapist? Not all children have GPs or a physiotherapist, so how do we ensure we're not missing anyone?

Most children are connected to physiotherapist through early intervention and school-age programs. In addition, the surveillance program might increase their ability to have more regular physiotherapist appointments.

In schools, the primary need/focus is not hip assessment, and there may be difficulty doing the assessment as physiotherapists don't have a plinth in the school setting.

Hip surveillance could be taught to medical students, as there are more doctors than physiotherapists.

Many children come to an orthopaedic surgeon from a clinic.

## X-ray

There is a vast geography and expertise of the technicians, and even one person repeating the same reading can have variation in the measurements they make.

In Australia, a dedicated team reads the x-rays. X-rays are often done in same facility, but when not, the picture and guide are provided so that the tech knows what positioning is required.

Is it feasible or desirable to have one radiologist reading all x-rays? This must be practical and feasible in all our environments.

Reimer's Migration Index slide: care is needed when measuring the Migration Percentage, as there could be 10% variation depending on where the vertical line is drawn. Attempting to standardize this comes back to one person reading the x-rays. If there are multiple people, then guidelines are required.

A tight program with strict criteria is needed, as is a joint effort between radiology techs and physiotherapists in positioning patients to meet the standard.

A surgeon won't make surgical decision based on one x-ray on one occasion, but on progression over time. If surveillance is done properly, and starts early, the trending will be evident.

It is important to separate surveillance from decision-making for treatments; in addition, there is concern with additional radiation.

Should just one film be done, or also a frog lateral?

### **Decisions**

- ❖ There was general consensus that most of the above points comprise implementation rather than guideline issues.
- ❖ In terms of number of films, the orthopaedic surgeons agreed that an AP of the pelvis is sufficient for surveillance.

## **Clinical Examination**

### Clinical exam vs. x-ray

Are these signs and symptoms to precipitate an x-ray? If not, what added value will they give to the x-ray?

What is the purpose of clinical assessment: to decide whether child needs an x-ray, or surgical consultation?

The clinical exam should be done around the same time as x-ray. Hip subluxation can be silent, which is why the x-ray is required; however, there may be other indicators that would precipitate a referral to an orthopaedic surgeon

The physical examination will show a trend in a child that may not have been scheduled to have an x-ray for the next two years.

The clinical exam will also assess the child's GMFCS level, which will prompt a physical examination and/or an x-ray depending on child's age.

### Details of Clinical Examination

The document does not provide details of the clinical exam; this needs to be comprehensive and explicit.

From a practical perspective, if the purpose of the screening is to decide whether child needs to see a surgeon, doctors and physiotherapists need to know what criteria are the most indicative, and actual cut-offs

The guidelines present minimum standards. As there is no evidence on exact values, trending over time must be looked at

In some more isolated areas, a physiotherapist will be performing the exam, and consistency about how this is done (positioning, angles, etc.) will be the key for moving that child to the next step.

The clinical exam should look at how tight the adductors are; this should go along with the x-ray. The Australian guidelines do not specify how often to x-ray based on how tight the adductors are.

If there is an abduction contraction that is interfering with caregiving or something, regardless of what the x-ray shows, this should be a red flag. What technique is used is a secondary question? Range of motion is a proxy for this, but what the range of motion might be is debatable.

In a clinical exam, how does the doctor or therapist categorize which symptoms relate to hip, and/or to something else?

The assessments are not just for hips; in a patient/family centred approach, hip is a key issue, but all information is important for the doctor or surgeon to know the patient as a whole.

There is a need to think about that clinical care pathway for children with CP from a very broad perspective, and hip surveillance is a part of that; however the focus of this list is the hip.

Pain is not included as a measurement in the musculoskeletal assessment, when it is often the first indicator.

In addition to the musculoskeletal assessment, doctors/physiotherapists should also look at pain, care, comfort, and changes in gross motor and gait.

An x-ray with a migration percentage is one red flag; whether abduction of 30 degrees or less is a red flag is debatable. However, pain or contracture that interferes with caregiving, regardless of what the x-ray says, is a problem for parents.

In the Swedish guidelines, in terms of pure hip surveillance, there was only one test: hip abduction range. All the other tests are important for orthopaedic management, but for surveillance, are the other tests useful? What is the Positive Predictive Value of a Tardieu test?

Is there any value to doing both a modified Tardieu and modified Ashworth? (There was consensus from the group that the Tardieu is enough).

The purpose of the guidelines is to prompt a referral to the orthopaedic surgeon. Much of what is in the Australian guidelines is for research purposes, therefore the list can be shortened in the context of hip surveillance. Surveillance must be kept simple.

In the guidelines Document 1, p.5, "Referral to an orthopaedic surgeon should occur when..." Is this to be included in the surveillance package without the guidelines? The fact these are presented separately might confuse people.

In Sweden, hip abduction is done with the knees flexed, to try to eliminate hamstring contribution. However, many are taught to do it with knees extended. Which is our standard?

Do we specify if internal and external rotation are measured in prone? — Ideally the child should be measured in prone, but this depends on whether or not the physiotherapist can get them into prone.

### **Indicators for referral**

GMFCS is key because of its prognostic value and reliability

What is minimum dataset for different age groups?

Gait pattern: How many hemiplegics will demonstrate a type IV gait pattern at age 12 and 24 months? Can we expect someone in the community to understand the complexity in identifying gait patterns at this age?

Internal rotation: the majority of children with CP have persistent anteversion

Spine, pelvic obliquity – this is useful information, but is it a red flag? Spine is only an issue for older children.

Leg length – how will this be measured? Most children with CP are asymmetric.

What is positive predictive value of any of these signs? Are there duplications? If the Positive Predictive Value is unknown, then many people will be put to more work without any benefit to the child.

If a migration of x% flags a referral, then what is the added value of something else?

Whom do the surgeons want to see, based on what?

For the clinical exam, regardless of what the x ray shows, the red flag would be an abduction contracture that interferes with caregiving.

A third indicator would be pain — regardless of other two indicators — that interferes with child's QOL, as best as can be ascertained that it's coming from the hip.

## Summary

The clinical exam will include the following measures and indicators:

- GMFCS Level / Gait pattern

  - Hip abduction

  - R1/R2 (Tardieu)

- Thomas test

  - IR/ER

- care and comfort

- pain

- spine / pelvic obliquity

- leg length

- ❖ The Ashworth test was removed from the list
- ❖ A subgroup may be needed to review the clinical exam list and in particular the comfort and pain measures

## Summary of Discussion

1. The context of all of this has to be a family-centred approach that is focused on good outcomes for the child and family
2. The group talked about how good surveillance is done so it can lead to appropriate early management, and the discussion unveiled a combination of surgical and non-surgical interventions. While everyone has personal experiences, there is still a relative lack of evidence about which approaches are most effective, using approaches measured in a standardized way
3. In BC, there is an incredible opportunity to study the comparative effectiveness of standardized practice patterns.
4. Is there agreement among the group that we need to look at a standardized way of doing surveillance for the province of BC?

## Consensus questions

### **1. There was agreement among the group that surveillance needs to be standardized.**

It is also critical to understand how this information will be used and acted upon.

### **2. There was agreement among the group that GMFCS levels should be used as basis for surveillance.**

### 3. Components of Guidelines

Several of the numbered items in the *Annotations and References for the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care, 2008, Document 2 of 3* were then discussed in detail; the discussion points are outlined in the following section.

## Discussion of Australian Consensus Statement Annotations

**1. Hip surveillance**– there was agreement on this definition and description.

**2. Cerebral Palsy** – this definition has since been superseded by the Red Journal definition, published by the NIH consensus group. The latter definition was deemed to be more appropriate for BC.

**3. Progressive hip displacement, dislocation and sequelae** – the group agreed on this definition and description

### 7. Radiological measures

There was concern around the word 'reproducible'; there needs to be more training and strict criteria around technique for taking and interpreting images.

- ❖ Question: how would you get the correct positioning for a patient with severe hip adductor contracture

### 8. Clinical Assessment

Question: Should this vary level by level, as opposed to being the same for every level?

Questions re: puberty and bone growth velocity: What test(s) should be used to identify puberty (hand x-rays, Tanner staging, age); who should do it (GP, paediatrician, physiotherapist); and what correlations are there between puberty, bone growth, growth velocity, and age?

- ❖ The group decided to discuss the guidelines by GMFCS level and then see if puberty comes up as an issue (*puberty was not included in the BC Consensus for Hip Surveillance so no consensus on the definition was required*).

### 11. Antero–posterior pelvic radiograph

We want to come up with a reasonably simple, reproducible way of getting a radiograph anywhere in the country that provides us with enough info that someone else can act on that information. We need to standardize radiographs in a pragmatic way, e.g. legs in neutral position; and we need to strike balance between something that's simple and something that's overly detailed and not feasible.

### 15. Normal/abnormal migration percentage

The group discussed what migration percentage should be used, as some use 30%, but a decision for surgical intervention might be made at 40%.

- ❖ The group agreed that for the purposes of surveillance, 30% should be the trigger for being flagged as at-risk; the guidelines are not looking at interventions.

There was some confusion around the use of 10% in #3, and 10% and 30% in #15.

There may need to be clarification of a 30 degree migration index versus 10% **change**.

Some hips by radiographic definition of >10% are subluxed, but below a certain threshold may stay there or even improve, whereas above a certain threshold are at risk for progression. This is why 30% has been picked; and this is different from 30 degrees on the acetabular index.

### 16. Puberty

There was some concern about the weakness of the definition of puberty in the document, and how puberty should be measured.

Bone age

- Study with Stevenon on growth in CP: international group spent time thinking about how to define puberty. Underlying neurologic status associated with puberty. Decided to use bone age because it was the most reliable source of information.
- This adds another x-ray, and radiation is a concern
- Bone age is not done for surveillance, it is done to see if the child is growing or not
- Concern about using bone age to predict anything apart from skeletal maturity

#### Tanner staging

- This depends on who is assessing the child; e.g. is it appropriate for a physical therapist to look at the genital area? There are issues of privacy.

#### Chronological age

- Given that all the other guidelines are age-related, can we just say "around age x" we want to start surveillance again?
- Age of puberty can vary greatly from age 8 to 14

The group then discussed whether puberty needed to be included in the guidelines.

How does knowing puberty stage change what the orthopaedic surgeons do?

Why do we need to know Tanner staging?

There is uncertainty about impact of puberty. Conceptually, rapid growth = higher risk.

What evidence is there that peak growth velocity occurs at puberty, for Children with CP, and its effects on hip instability? This has not been studied systematically in this context.

Do we change our surveillance based on this?

Is puberty too much of an issue in the guidelines? Hip instability does not happen in isolation.

The purpose of hips surveillance is the younger child, and early intervention.

## Summary

More thought and discussion are needed around:

1. The use of other x-rays;
2. How the information has been collected and used in other places
3. Tanner staging – particularly implementation issues

*Authors of the Australian Consensus statement were contacted after the meeting and report that pre puberty is assessed by the paediatrician or community physio as per the annotation. This is not strict; the idea was to allow those children with low and stable migration percentage to avoid unnecessary X-rays, so the age of 11 for girls and 13 for boys is okay as a guide as well.*

### **#20–25: clinical assessment questions**

The group decided to leave these for the discussion by GMFCS level.

## Appendix B: Discussion of Guidelines by GMFCS Level

The group then discussed specific guidelines for each of the GMFCS levels. The discussion points are listed below; for the agreed-upon BC guidelines, please refer to the body of the conference report.

### General discussion points

Standardizations need to be clinically relevant

Keep it simple and uniform for everyone

A balance must be struck between overuse of resources and under-surveillance

GMFCS levels are most accurate after the age of 2

### GMFCS V

Currently, it is very ad hoc who gets sent to an orthopaedic surgeon at what age, if they're not showing signs of spasticity, reduced range of motion, or pain.

CDCs have done great clinical systems over years but this has not prompted the shifts in orthopaedic care.

At this level, migration can happen quickly (6 months).

The high-risk children are already in intervention.

Some children are not diagnosed until age 4 or 5. The therapist or doctor thinks they have CP (they show clinical signs), but the neurologist wants to do tests, which take time. This should perhaps be added into the guidelines: not only diagnosis but CP symptoms.

Why did Australia choose 12 months as the starting age?

— There is evidence that changes in migration can happen as early as one year of age.

There is no surgery at this age, but there may be other interventions, such as bracing. In addition, the family needs to understand that there's a problem.

Surveillance is predicated on idea that early detection allows early intervention. If there isn't evidence to support that early intervention makes a difference or will help with decision making, the Australian guidelines must be questioned, because they translates into additional resources and cost. The reason the Australians start this early is the opportunity to do research; they admit the evidence is weak.

Entry point is being based on the x-ray, but it is less expensive to base entry point on clinical assessment. This will expose the children to less radiation, and it is more accessible for most children.

The clinical exam isn't a reliable way of indicating when an x-ray is required as migration is silent.

Children with significant muscle tone are already in the system and being seen, but ones with significant hypotonia, and not having significant contractures or orthopaedic anomalies might be not have seen an orthopaedic surgeon by 24 months.

Most GMFCS Vs would be referred by other symptoms, so this group would have a high level of people watching them. So Q12 months might be sufficient for x-rays.

This is the highest risk group, but also the group getting the highest level of attention. It may be that the GMFCS II, III and IVs are at more risk because they are receiving less attention from the system

Surveillance should not replace clinical care that's already on track. We are looking at the children potentially being missed because they don't have the right doctor referring them to the right person

Parents are dealing with feeding, reflux, seating, etc.; it is hard to throw another appointment at them when they have other conditions going on. The hip is not top priority with the parents at that point

Hip abduction should be a factor in how often the x-rays are needed

### GMFCS IV

There is not a great difference between GMFCS IV and V, so the guidelines should not differ greatly

Should the GMFCSV guideline be replicated? Why is there any difference among non-ambulatory CP? In Sweden, the III, IV, and Vs are the same

At age 2, we don't know if they are a IV or a V

GMFCS IV has a 70% statistical incidence developing an unstable hip. If this is quoted, parents will understand the concern

If we start with Q6 for x-rays, do we need 10 x-rays to decide if they are stable?

For hips that are stable and under 30%, can we drop to Q12 months until skeletal maturity?

How do we define 'stable'? — Some members of the group liked the idea of 'until stable' as it gives a bit of wiggle room. The upside of this is it permits individualization; the downside is that it leaves holes, because people are confused

Who decides if they are stable/unstable?

Why does Sweden not look at stable/unstable issue?

If the patient is not stable by age 6, they would have already seen an orthopaedic surgeon. If they progress rapidly, it's in 3-6 age group. After that, they tend to progress more slowly.

If by now these patients are referred to orthopaedic surgeons, should the issue of stable/unstable be removed, and the surgeons decide?

— This assumes that the orthopaedic surgeon will keep them under their care consistently until skeletal maturity, but doesn't always happen; sometimes they see the surgeon once, then not again for years.

Practices might be different, and we're coming up with guidelines

If frequency is based on chronological age, what happens if an exam or x-ray is late? — The dates are for reminders, not logistics. At the same time, we want to avoid the 'birthday system', and we need parents and providers to realize we don't need them to 'catch up'.

With the age system, there is less risk of them falling through the cracks. This is not the care of children, this is a safety net.

The families won't get a plane flight every 6 months.

6 to 6 is easy to remember; people need something basic when they fill out a requisition.

Should migration percentage replace the word 'stable'? If <30, the frequency drops to 12 months; if over 30, it remains at 6 months?

The document should state up-front that at 30%, they are referred to an orthopaedic surgeon.

Will there be unnecessary x-rays? — That is the nature of screening.

12 months is the frequency for surveillance; in clinical reality, x-rays may be done sooner.

There was concern about the word 'at diagnosis' because many children don't have diagnosis at that age. (The term used in the document was 'identification' rather than 'diagnosis')

Canada and Australia are similar in terms of geography: big distances, resulting in long drives. Sweden is smaller. However, from a funding perspective, Canada is more like Sweden; Australia is a two-tiered system

### GMFCS III

This group is at risk for instability about 40% of the time, but not until much later. Q12 months (per Sweden) is sufficient, but the age could be extended because this group is at continued risk; displacement happens more slowly than for the IVs and Vs.

An important factor is whether the child can take 10 steps by 30 months. This is a determinant of whether they will continue to displace.

Is there much difference between the ages of 6 and 12?

— A lot of interventions happen from ages 8-10

Range of abduction could be used as a trigger. This can minimize the x-rays.



Separating clinical exams and x-rays has not yet been looked at; the clinical exam could be annual, and x-ray every 2 years

The triggers are migration >30%, pain at any time, and contracture interfering with caregiving. The clinical exam should happen annually

Every time there is a clinical exam or x-ray, GMFCS level should be reviewed. IIIs are particularly the ones that may change

GMFCS should be reviewed at time of clinical exam, for all levels

Pre-puberty should be taken out (per earlier discussions)

What is the indicator for skeletal maturity?

There was concern with abduction not precipitating an x-ray? If the child has an abduction contracture, how quickly do they need to be seen by an orthopaedic surgeon?

If hip abduction <30 should there be an x-ray? With some orthopaedic surgeons, this would warrant an intervention regardless of what the x-ray looks like.

#### Decisions:

- ❖ Overall guidelines for referrals to orthopaedic surgeons still need to be worked on
- ❖ Closure of the triradiate cartilage will be used to indicate skeletal maturity

## GMFCS II

The annual clinical exam should verify GMFCS level, rule out hemiplegic gait type IV, and look specifically at abduction. If HA<45, this triggers an x-ray

The Is and IIs could be grouped together, as they are at very low risk.

Should the Is be dropped from the guideline? Sweden does nothing automatically for level I.

In practice it is difficult to know if a I becomes a II until they are older. For GPs, description of GMFCS I is still useful (it looks strange if it's missing). Even in a gait lab there can be debate about whether a child is a I or a II. Plus, someone needs to be making sure they are still a I.

Why do the Australian guidelines have an x-ray so young for GMFCS II? Is this because they would be missed otherwise, or is it for research?

— Their guidelines are supported because they have a CP registry; they have a mechanism for identifying the children.

A takeaway task is to talk to our Australian and Swedish colleagues to see if there is any evidence that we wouldn't be missing many children

For simplicity, an ambulatory child without a walking aid (i.e. Is and IIs) could have one x-ray at age 4 or 5.

Is Type IV gait being separated out? Because a Type IV gait will never be a I; that child would be a II or III.

Type IV gait should not be in level I, II or III, but described as a unilateral CP.

If GMFCS and gait type are verified annually, hopefully the silent IVs won't be missed

Change of gait is complicated as there are so many ways gait can change. This would be a whole other education piece. The guidelines need to be simple. A GP doesn't know what type IV gait is, but can easily check what hip abduction is.

Gait Type IVs should be referred to an orthopaedic surgeon, with annual follow-up by the surgeon after that.

Suggestion: hip abduction of  $x^\circ$  to trigger an x-ray; if the range is greater, then 1 x-ray at school entry age

What degree of hip abduction are we using for all GMFCS levels? (Suggestion: 30° rather than 45°)

Should the hip abduction range (30 degrees) be specified for this group? It was not for the IVs or IVs; the triggers for referral were limited hip abduction interfering with caregiving; pain; MP of >30%. The reason

abduction is not as important for the IVs and Vs is that they can still have good range but a bad hip; and they are getting x-rays every 6 months in any case.

Defining restriction in hip abduction should also be a trigger for GMFCS III.

If the child's gait has changed significantly, this should prompt a referral; the exact hip abduction range is not as important. Will a GP remember what the gait was previously? A surveillance program will require that proper notes are taken. In addition, the parent will remember.

The families need to know that they should be asking for a clinical assessment, particularly for hip abduction.

GMFCS Is and IIs are often not being seen by a therapist, either school age or early interventionist. So who would do this assessment? We have to assume it's more likely to be GPs and paediatricians

If we are targeting GPs, we need a communication plan around what would trigger referral to paediatric therapist: for the lower GMFCS levels, at identification refer to a paediatric therapist.

Rural GPs don't always have access to therapists, so this rule might make us lose this child.

A surveillance program in a rural setting will have a team of people doing the surveillance. Hopefully there will be improved communication between the GP and physiotherapist through this initiative.

If the guidelines have proper descriptions of tests, investigations, how they're done, specifically around how to do the Tardieu, Thomas test, etc. most family physicians could do this.

This is for hip surveillance, whereas referral to a physiotherapist is more for development, strength, etc.

Is referral to a paediatric therapist just for GMFCS II? This should be an overarching comment for all levels.

### Decisions for all levels

- ❖ GMFCS should be reviewed at time of clinical exam, for all levels.
- ❖ GMFCS I and II should be grouped, as Is still need reassessed to see if they have become IIs, and the types can be hard to distinguish in many cases.
- ❖ Type IV gait should not be in level I, II or III, but described as a unilateral CP. In addition, take out the term 'Winters Gage and Hicks' and leave it as 'Hemiplegic type IV'.
- ❖ The document should say up-front that at 30% MP, children are referred to an orthopaedic surgeon.
- ❖ The term 'identification' should be used instead of 'diagnosis'.
- ❖ 'Pre-puberty' should be taken out.

## Appendix C: Takeaway Tasks

### **GMFCS II - x-ray age 2**

Talk to Australian and Sweden colleagues to see if there any evidence that we would miss many children if we don't perform an x-ray this young

### **Puberty and age**

Ask the group's Swedish and Australian colleagues what evidence they have from data collected so far on the relationship between puberty and age. From a research perspective this is interesting, but what is its role in practical implementation?

### **Terminology**

Consensus is needed on the definition and use of the terms screening, surveillance, and evaluation.

### **Guidelines Document**

- Consensus must be achieved regarding elements of physical exam

Overall guidelines for referrals to orthopaedic surgeons still need worked on

## Appendix D – Planning Committee and Attendees

### *Planning Committee Members (in alphabetical order)*

No.	Name - Last	Name - First	Job Title	Health Authority	City	Prov
1	Duiveststein	Janice	Program Manager	Sunny Hill Health Centre for Children	Vancouver	BC
2	Lanphear	Nancy	Senior Medical Director	Sunny Hill Health Centre for Children	Vancouver	BC
3	Matthews	Mary Lou	Manager, Child Health BC	Child Health BC	Vancouver	BC
4	Miller	Stacey	Physiotherapist	BC Children's Hospital	Vancouver	BC
5	Mulpuri	Kishore	Orthopaedic Surgeon	BC Children's Hospital	Vancouver	BC
6	O'Donnell	Maureen	Executive Director	Child Health BC	Vancouver	BC
7	Roxborough	Lori	Therapy Associate Director/Outreach Manager	Sunny Hill Health Centre for Children	Vancouver	BC
8	Steenburgh	Suzanne	Program Manager	BC Children's Hospital	Vancouver	BC
9	van Rensburg	Esias	Developmental Pediatrician	Sunny Hill Health Centre for Children	Vancouver	BC

### *List of Attendees (in alphabetical order)*

No.	Name - Last	Name - First	Job Title	Health Authority	City	Prov
1	Acharya	Ashok	Orthopedic Surgery Fellow	BC Children's Hospital	Vancouver	BC
2	Aird	Natalie	Peditrician (General Consulting)	Vancouver Island Health Authority	Comox	BC
3	Alvarez	Christine	Orthopedic Surgeon	BC Children's Hospital	Vancouver	BC
4	Banks	Sylvia	Physiotherapist	private practice	Vancouver	BC
5	Black	Alec	Director, Shriners Gait Lab	BC Children's Hospital	Vancouver	BC
6	Boda	Lisa	District Physiotherapist	School District #60	Fort St. John	BC
7	Boyd	Fran	Vice President, CDR/SHHC	BC Children's Hospital	Vancouver	BC
8	Bucknor	Garnett	Admin Assistant	Child Health BC	Vancouver	BC
9	Byron	Patti	Director Patient Care Services, Specialized Pediatrics	BC Children's Hospital	Vancouver	BC
10	Cairns	Robyn	Pediatric Radiologist	BC Children's Hospital	Vancouver	BC
11	Cameron	Dianne	Director of Therapy Services	Non-profit with MCFD therapy contracts	Vancouver	BC
12	Cox	Kim	Physiotherapist	FVCDC	Chilliwack	BC
13	Davidson	Kathy	OT/PT Coordinator	Penticton Child Development Centre, MCFD Contract funding	Summerland	BC
14	Dawson	Denise	ECD/CYSN Interior Region Consultant	CYSN/MCFD	Vancouver	BC
15	Duiveststein	Janice	Neuromotor Program Manager Sunny Hill	BC Children's Hospital	Vancouver	bc
16	Elliott	Karol	Physical Therapist and Occupational Therapist	School District 23 Student Support Services	Kelowna	BC
17	Evans	Janice	Section Head PT	BC Children's Hospital	Vancouver	BC
18	Fawdry	Brent	Director of Physiotherapy	Ridge Meadows CDC (MCFD funded)	Maple Ridge	BC
19	Gordon	Jason	Provincial Paediatric Therapy Recruitment and Retention Coordinator	mcf	Kelowna	BC
20	Hilliard	Mike	physiotherapist	Vancouver Coastal Health	Vancouver	BC
21	Katsube	Colleen	Pediatric PT	Fraser Health Authority	Surrey	BC
22	Keith	Patty	Regional Director of Planning, Maternal/Child, Regional Programs and Service Integration	Vancouver Coastal Health Authority	Vancouver	BC
23	Lanphear	Nancy	Senior Medical Director, Sunny Hill	BC Children's Hospital	Vancouver	BC
24	MacLeod	Kim	Physiotherapist	Interior Health Authority	Kelowna	BC
25	Matthews	Mary Lou	Manager, Child Health BC	Child Health BC	Vancouver	BC
26	Mayson	Tanja	Gait Lab Physiotherapist	BC Children's Hospital	Vancouver	BC
27	McIlwaine	Maggie	Professional Practice Leader Physiotherapy	BC Children's Hospital	Vancouver	BC
28	Meaning	Shirley	CYSN Therapy Manager	Ministry of Children and Family Development	Victoria	BC
29	Miller	Stacey	Physiotherapist	BC Children's Hospital	Vancouver	BC

30	Mulpuri	Kishore	Pediatric Orthopedic Surgeon	BC Children's Hospital	Vancouver	BC
31	Narayanan	Unni	Assistant Professor/Scientist	The Hospital for Sick Children & Holland Bloorview Kids Rehabilitation Hospital, University of Toronto	Toronto	Ontario
32	Nelson	David	Orthopaedic Surgeon	Northern Health Authority	Prince George	BC
33	Newell	Veronica	Director of Physiotherapy	The Centre for Child Development	Surrey	BC
34	Norgrove	Penny	Head, Division of Paediatric Surgery	Vancouver Island Health Authority	Victoria	BC
35	North	Llaesa	Director of Physiotherapy	Child Development Centre of Prince George	Prince George	BC
36	O'Donnell	Maureen	Executive Director, Child Health BC	Child Health BC	Vancouver	BC
37	Pirani	Shafique	Paediatric Orthopaedic Surgeon	Fraser Health Authority	New Westminster	BC
38	Pryce	Bonnie	Charge Physiotherapist	Interior Health Authority	Kamloops	BC
39	Purtzki	Jacqueline	Physiatrist	BC Children's Hospital	Vancouver	BC
40	Roxborough	Lori	Therapy Assoc Director & Outreach Manager	BC Children's Hospital	Vancouver	BC
41	Silver	Taryn	Staff Physiotherapist	Nanaimo Child Development Centre	Nanaimo	BC
42	Sims	Donna	Staff Physiotherapist - Grade II	Vancouver Island Health Authority	Victoria	BC
43	Steenburgh	Suzanne	Program Manager for Neurosciences and Surgery	BC Children's Hospital	Vancouver	BC
44	Strydom	Jaco	Physician	Northern Health Authority	Terrace	BC
45	Therriault-Finke	Christine	Physiotherapist	Kootenay Family Place	Castlegar	BC
46	van Rensburg	Esias	Developmental Pediatrician	BC Children's Hospital	Vancouver	BC
47	Warcup	Margaret	Executive Director	Kitimat Child Development Centre	Kitimat	BC
48	Willms	Brenda	Orthopedic Nurse Clinician	BC Children's Hospital	Vancouver	BC
49	Xu	Kaishou	Rehabilitation Specialist	BC Children's Hospital	Vancouver	BC



Child Health BC  
4088 Cambie Street, Suite 305  
Vancouver BC, V5Z 2X8  
T: (604) 877 6410  
F: (604) 874 8702  
[www.childhealthbc.ca](http://www.childhealthbc.ca)  
[info@childhealthbc.ca](mailto:info@childhealthbc.ca)  
In Partnership with:  
The Neuromotor Program  
at Sunny Hill Health Centre for Children  
& Department of Orthopaedics  
at BC Children's Hospital