



**Interprofessional Consensus
Meeting**
**Implementing the British
Columbia Consensus on Hip
Surveillance for Children
with Cerebral Palsy**

***January 26-27, 2012
Granville Island Hotel, Vancouver BC***

Final – June 19, 2012

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Executive Summary

In May 2011, a multidisciplinary group with representation from all regions of the province, met over 1.5 days, to discuss hip surveillance in British Columbia (BC). Evidence regarding hip surveillance, including that of existing programs in Australia and Sweden, was discussed. Meeting attendees established consensus regarding the desire to create a BC hip surveillance program for children with cerebral palsy (CP) and similar conditions based on four sub-groups: Gross Motor Function Classification System (GMFCS) levels (1) I & II; (2) III; (3) IV & V and (4) children with Winters, Gage, & Hicks Type IV hemiplegia. Consensus was reached on the commencement of surveillance, the frequency of radiographs, and the frequency of clinical exams for each of these sub-groups. This established the **British Columbia Consensus on Hip Surveillance for Children with Cerebral Palsy**, referred to as the **Consensus Statement** throughout the report. The full discussion surrounding the creation of these standards is included in the report dated May 2011.

In January 2012, a second 1.5 day meeting was convened to establish consensus on a preferred model for implementation. Regional representatives from multidisciplinary perspectives received presentations on the Consensus Statement and potential models for implementation. These were then discussed as a group and by health regions. Revisions were made to the Consensus Statement and the final standard for the BC Consensus on Hip Surveillance for Children with CP was agreed upon. These changes include the:

- Definition of 'Similar Conditions'
- Elements of the Clinical Exam
- Frequency of Hip Surveillance
- Criteria for Referral to Orthopaedics

Three potential models for implementation were presented to the group and a preferred implementation model was selected. This preferred model includes program coordination by a provincial coordinator and utilizes a data management system to track children. Strategies for implementation of this model were developed based on maximizing the resources available within the province. The agreed upon preferred implementation model is detailed within this report.

Knowledge transfer and evaluation plans were also addressed. Knowledge translation considerations, methods, and recommended content were presented and attendees identified what information relating to the program should be communicated and to whom. Evaluation of knowledge translation methods, adherence to the Consensus Statement, and patient and family outcomes were identified. Attendees agreed that the Consensus Statement will be reviewed by the group in three years.

The conference concluded with an agreement of the next steps in moving towards implementation of a provincial hip surveillance program. These include mechanisms for creating and supporting the role of the provincial hip surveillance coordinator, developing a program database, and creating effective knowledge translation and quality improvement initiatives.

About this Meeting

Meeting Summary

A consensus statement on hip surveillance for children with cerebral palsy (CP) in BC was developed at an interdisciplinary meeting in May 2011. The purpose of the second meeting in January 2012 was to develop an implementation plan for the consensus statement on hip surveillance in BC. A multidisciplinary group including parents and professionals, with representation from all regions of the province, were in attendance (see Appendix A).

Four themes emerged from the meeting:

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

Meeting Objectives

The three objectives of the meeting were:

1. To review the BC hip surveillance consensus statement established at the May 2011 meeting.
2. To obtain consensus using new information regarding the physical exam portion of the Consensus Statement.
3. To gain agreement on province-wide implementation of the Consensus Statement.

About this Report

What follows is a summary of the January meeting and the discussions involved. Presentations are summarized and conclusions that were made by the group are highlighted. The finalized consensus on hip surveillance in BC and the preferred implementation model, which were agreed upon during the meeting of January 26/27, 2012, are presented. The report details the plan for knowledge translation and evaluation and concludes with participant recommended next steps for creating a provincial hip surveillance program.

Meeting Summary

Setting the Stage: Background, Current Context & Preferred Future Vision

Summary of Presentation by: *Dr. Kishore Mulpuri, Paediatric Orthopaedic Surgeon, BC Children's Hospital*

Hip displacement is the second most common musculoskeletal deformity affecting children with cerebral palsy (CP) after equinus. Reported rates of hip displacement and dislocation in children with CP vary widely - between 2% to 75%. In three population studies, the rate of hip displacement was found to be one-third. Dislocation of the hip in CP results in significant morbidity.

Early detection is the key as it will lead to early intervention. Hip surveillance programs have been shown to prevent/reduce hip dislocation in children with CP and avoid the need for salvage hip surgeries. However, at BC's Children's Hospital, up to one third of hip surgeries performed in a one year period in 2008-2009 were salvage procedures for painful dislocated hips.

The implementation of a BC hip surveillance program will increase the early detection of hip displacement. In turn, this will permit appropriately timed intervention, reduce or eliminate the need for salvage surgery, and reduce morbidity.

Current Context: A Parent Perspective

Summary of Presentation by: *Michelle Gentis, mother of a child with cerebral palsy*

Michelle introduced her son Joshua who is cognitively bright, socially full of heart, and in his mind an athlete. They are determined to keep fit and healthy in order to live an active and happy life. As a parent Michelle stated she was unaware of the possibility of progressive hip displacement. Just a year prior to the hip surgery Joshua required, he had no pain but Michelle saw deterioration in his ability to stand. As a single mom Michelle needed Joshua to stand to help with day-to-day chores as dressing and washing. She realized that if he lost the ability to stand or walk assisted it would be devastating for them. When the orthopaedic surgeon proposed the surgery, he asked if they wanted to think about it, but there was no need. It was a definite yes. The surgery was major with a long recovery but Joshua is gaining back his leg strength.

Michelle thanked everyone for being there, for working toward developing a program that would identify early hip displacement and for thinking about the whole child and his/her family.

British Columbia Consensus Statement

Summary of Presentation by: *Stacey Miller, Physiotherapist, BC Children's Hospital*

At the January meeting, the content of the May 2011 workshop on hip surveillance was reviewed. At this previous meeting, a multidisciplinary group with representation from all regions of the province, met over 1.5 days, with the goal to reach consensus on a standard of care for hip surveillance in BC. Evidence regarding hip surveillance, including that of existing programs in Australia and Sweden, was discussed. Meeting attendees established consensus regarding the desire to create a BC hip surveillance program for children with CP and similar conditions based on four sub-groups: Gross Motor Function Classification System (GMFCS) levels (1) I & II; (2) III; (3) IV & V and (4) children with Winters, Gage, & Hicks Type IV hemiplegia. Consensus was reached on the commencement of surveillance, the frequency of radiographs, and the frequency of clinical exams for each of these sub-groups. This established the **British Columbia Consensus on Hip Surveillance for Children with Cerebral Palsy** here after referred to as the **Consensus Statement**.

Definition of CP and Similar Conditions:

After reviewing the Consensus Statement, the need to define “similar conditions” was discussed. It was proposed and approved that the definition of “similar conditions” used in the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care of “ (Wynter et al., 2008) be adopted. The definition is as follows:

Definition of Similar Conditions

- “Like conditions refers to those conditions where motor dysfunction results from genetic and metabolic aetiologies, including clearly recognized syndromes or progressive brain disorders (Badawi et al., 1998), or from brain injury acquired in childhood within the first 2 to 3 years of life”.
- Motor disorders of spinal, peripheral nerve, muscular, or mechanical origin are not considered as “like conditions”.
- Disorders of impaired cognition but no motor signs are not considered as “like conditions”.

Clinical Exam Consensus Building: Review of the Evidence

Summary of Presentation by: *Stacey Miller, Physiotherapist, BC Children's Hospital*

The components of the Clinical Exam were approved at the May 2011 meeting. However, at that time it was noted that further review of the literature was required. The following conclusions were presented at the January meeting:

- There is no evidence that hip displacement is related to range of motion (ROM) measurements
- Measurement of ROM is a poor indicator of risk but decreasing ROM over time could warrant radiographic hip exam
- Reliability of goniometric and tone measures are questionable
- A large change in ROM value is required to have confidence there has been a true change
- Measurement variation is less when measured by one tester

Prior to the January meeting, the pediatric orthopaedic surgeons in BC were asked for their expert opinion regarding the clinical exam and came to a small group consensus on the important elements and referral criteria. This small group consensus was then presented to and approved by the meeting attendees following discussion. The goal of the Clinical Exam is to ensure the child is referred for review of their hip status at the appropriate time. It is specifically about hip surveillance.

The consensus on the Clinical Exam is as follows:

Clinical Exam

Classify:

- Determine GMFCS level
- Identify Type IV hemiplegia

Measure:

- Hip abduction range of motion with hips at 0° flexion (R2 value)
- Dynamic contracture of adductors using the Modified Tardieu Scale (R1 value)
- Thomas test for hip flexion contracture

Ask:

- Does your child experience pain related to the hip? This may be noticed when changing your child's position, when you move your child's leg, or during daily activities such as diaper changing?
- Do you have more difficulty caring for your child during activities such as perineal care, dressing, bathing or other similar activities requiring hip movement?
- Has there been deterioration in your child's function, such as a change in their ability to walk or a decreased ability or tolerance of sitting or standing, which is related to the hip?
- Who is your family physician/paediatrician?

The consensus on the Criteria for Referral to Orthopaedics is as follows:

Criteria for Referral to Orthopaedics

The intention of this consensus statement is that review by a pediatric orthopaedic surgeon occurs at the appropriate time. A referral to an orthopedic surgeon should occur in the following situations:

- Migration Percentage (MP) > 30%
- Hip abduction end range (R2) is $\leq 30^\circ$
- Deterioration or asymmetry in:
 - Hip abduction (R1 or R2)
 - Thomas test
- Positive answer to any one of the three questions in the Clinical Exam
- Any other clinical concern that is felt to be related to the hip

Frequency of Hip Surveillance

During the meeting discussion, it was noted that children that are GMFCS levels I and II are at risk of missing the hip x-ray that is recommended at age 6. The original choice of age 6 for the radiograph for children GMFCS I and II was based on the Swedish model and provided continuity with the guidelines for GMFCS III, IV, and V. In BC, children typically transition from early intervention services prior to age 6 and may be lost in the transition to school therapy services or may not have access to therapy services once school aged. After a prolonged discussion, consensus was reached that children that are classified as GMFCS level I and II and/or have a Type IV gait pattern will have an initial x-ray at age 5 instead of age 6. Details of the discussion can be found in Appendix B.

The agreed upon Frequency of Hip Surveillance is as follows:

Recommended Frequency for Hip Surveillance

GMFCS I & II

- At each assessment, verify GMFCS level and identify children as hemiplegia Type 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 5 years of age with clinical assessment and antero-posterior (AP) pelvic x-ray
- If x-ray findings are normal at 5 years, discharge from surveillance

Hemiplegia (Hemi) Type IV

- Surveillance as per guidelines for GMFCS I & II up to 5 years of age
- After 5 years of age, until skeletal maturity, review with:
 - Clinical assessment 12 monthly
 - AP pelvic x-rays 12 monthly

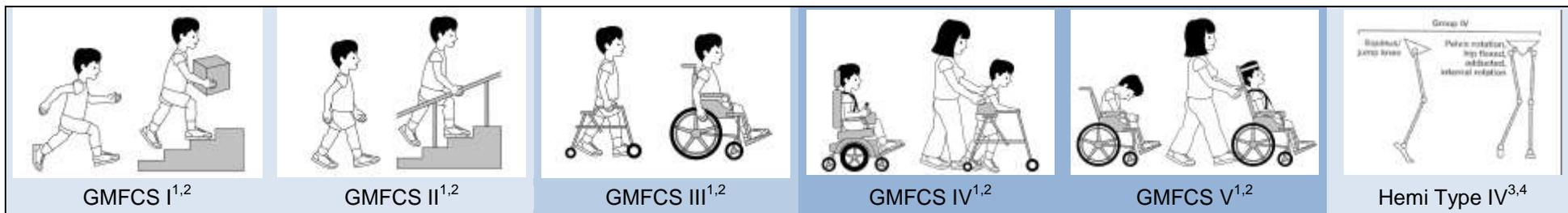
GMFCS Level III

- 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

British Columbia Consensus on Hip Surveillance for Children with Cerebral Palsy – Quick Guide



Classification Scale	Age in Years																				Until Skeletal Maturity			
	ID	2	2.5	3	3.5	4	4.5	5	5.5	6	6.5	7	7.5	8	8.5	9	9.5	10	10.5	11		11.5	12	
GMFCS Level I & II	C	C		C		C		C																
GMFCS Level III	C	C		C		C		C		C		C		C		C		C		C		C		C q1yr R q2yrs
GMFCS Level IV & V	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C q1yr R q1yr
Hemi Type IV	C	C		C		C		C		C		C		C		C		C		C		C		C q1yr R q1yr

Legend:

- C = Clinical Exam
- R = Hip Radiography
- q = Every
- GMFCS = Gross Motor Function Classification System¹
- Hemi Type IV = Winters, Gage, Hicks Hemiplegia Gait Classification Type IV³
- ID = Identification/Diagnosis of Cerebral Palsy or Gross Motor Delay
- Skeletal Maturity → Determined by closure of triradiate cartilage on radiograph

1. Palisano R. et al. Content validity of the expanded and revised Gross Motor Function Classification System. *Dev Med Child Neurol.* 2008;50:744-50.
2. Illustrations by Graham H.K. and Reid B., The Royal Children's Hospital, Melbourne, Australia.
3. Winters TF, Gage JR, Hicks R. Gait patterns in spastic hemiplegia in children and young adults. *J Bone Joint Surg.* 1987;69:437-441.
4. Illustrations by Rodda J. & Graham H. K. The Royal Children's Hospital, Melbourne, Australia.

BC Implementation

Summary of Presentation by: *Tanja Mayson, Physiotherapist, Sunny Hill Health Centre for Children and Stacey Miller, Physiotherapist, BC Children's Hospital*

BC Context: A Look at the Numbers:

An overview of CP in BC was presented to provide context to the discussion of implementation of a provincial hip surveillance program. The key highlights include:

- CP impacts 2-3 of every 1000 live births in BC
- There is currently no information regarding children with CP in terms of incidence or child characteristics
- An estimation based on 2008 BC STATS indicates there are up to 2600 children with CP living in BC
- Approximately 700 hundred of those children are under the age of 5
- An estimated 30% of children with CP are being followed by an Orthopaedic Surgeon

Key Questions for Implementation:

Five questions were identified as being key to determining how to successfully implement hip surveillance in BC. These questions and possible options were presented to the attendees. Delegates were divided into their regional health authorities and were asked to determine which options were most suitable to their region. Participants were asked to consider the following questions. Consensus was achieved for each question and is described here.

1. Who will identify the child?

Based on the regional discussion, it was noted that this question could be divided into three parts:

1a. Who will identify the child?

- Anyone can refer to Early Intervention Program(EIP) Physiotherapist (PT)
- This includes physician (MD), public health nurse (PHN), nurse practitioner (NP), parent, Infant Development Program (IDP) consultant, social worker (SW), etc.
- If unsure of where to access PT or if no EIP, contact hip surveillance coordinator

1b. Who will assess if referral criteria are met and enroll the child?

- PT
- If no PT then Occupational Therapist (OT)
- If no OT then a trained health professional or community partner (MD, PHN, NP, IDP)

1c. Who will complete clinical exam?

- PT
- If no PT then OT
- If no OT then a trained community health professional or community partner (MD, PHN, NP, IDP)

2. Who will manage surveillance?

- Unanimous agreement that one provincial coordinator is required
- Regional coordinators were not seen as necessary due to volume and risk of overlap
- Regional contacts to help manage and promote hip surveillance were supported

3. Is a Database required?

- Unanimous agreement that a database is needed to ensure systematic tracking

4. Who will request a radiograph?

- Provincial coordinator with delegation of function from orthopedic surgeon
- If no orthopaedic surgeon is involved, radiograph request with delegation of function from medical program director
- Family physicians, pediatricians and person completing clinical exam will be informed when radiograph request is sent to the parent
- During clinical exam, clarify which physicians are involved in care to assist with disseminating hip surveillance findings to appropriate care providers

5. Who will measure MP?

- Provincial coordinator or radiologist, initially both to evaluate validity and reliability
- Requires providing education to all radiologists and asking them to report MP
- Evaluate reliability of Coordinator and Radiologist with Orthopaedic Surgeon as gold standard to determine how to process in the future

Potential Implementation Models

Three potential implementation models for the hip surveillance in BC were presented to the delegates.

Model 1 (containing coordination and database) – See Figure 1:

This model was proposed as the preferred model for hip surveillance in BC. This model includes coordination by a provincial and/or regional coordinator and utilizes an electronic management system to manage information and flow through the program. The database and coordinator would help ensure consistency in completion of x-rays, clinical exam, communication with appropriate care providers, and timely referral to orthopaedics. This model requires the greatest dedication of resources.

Model 2 (containing coordination but no database, spreadsheet only) – See Figure 2:

Model 2 is similar to model one in that it includes coordination by a provincial or regional coordinator but differs in that it uses a spreadsheet instead of a database to manage information. The timeframes for communication are increased due to the manpower required to monitor the spreadsheet. There is a greater risk of missing children in the process. This model requires fewer resources than Model 1 but greater than Model 3.

Model 3 (containing no coordination or database/spreadsheet) – See Figure 3:

The third option illustrates the creation of a consensus for recommended practice for hip surveillance in BC through the use of educational materials. It does not constitute the creation of a hip surveillance program that will ensure systematic surveillance for children in the province but would promote transfer of knowledge. This model requires the fewest resources.

Following the presentation of these three models, delegates were divided into health authority groups and asked to determine the preferred model for their region and to provide suggestions for improvements. Based on these discussions, consensus was achieved that Model 1 was the preferred model for all regions of BC. Suggestions to improve the model were discussed and are included in the final version of the preferred implementation plan as shown in Figure 4. Highlights of the revisions to the preferred implementation model include:

- Anyone can identify a child
- Only provincial coordination is required with regional contacts
- Parents should be called by the provincial coordinator when a referral to orthopaedics is required
- Primary care physician should be advised when the x-rays requisition is sent to the caregiver and informed of outcome of surveillance

The possibility of starting with the spreadsheet and eventually moving to a database was discussed. The use of a spreadsheet requires a provincial coordinator. Concerns with managing the volume of data in an effective and timely manner were the primary concerns with using a spreadsheet.

Further discussion about the models can be found in Appendix B.

Figure 1

Model 1 Hip Surveillance Program: Program Coordination & Provincial Database
The Ideal Model for Provincial Implementation

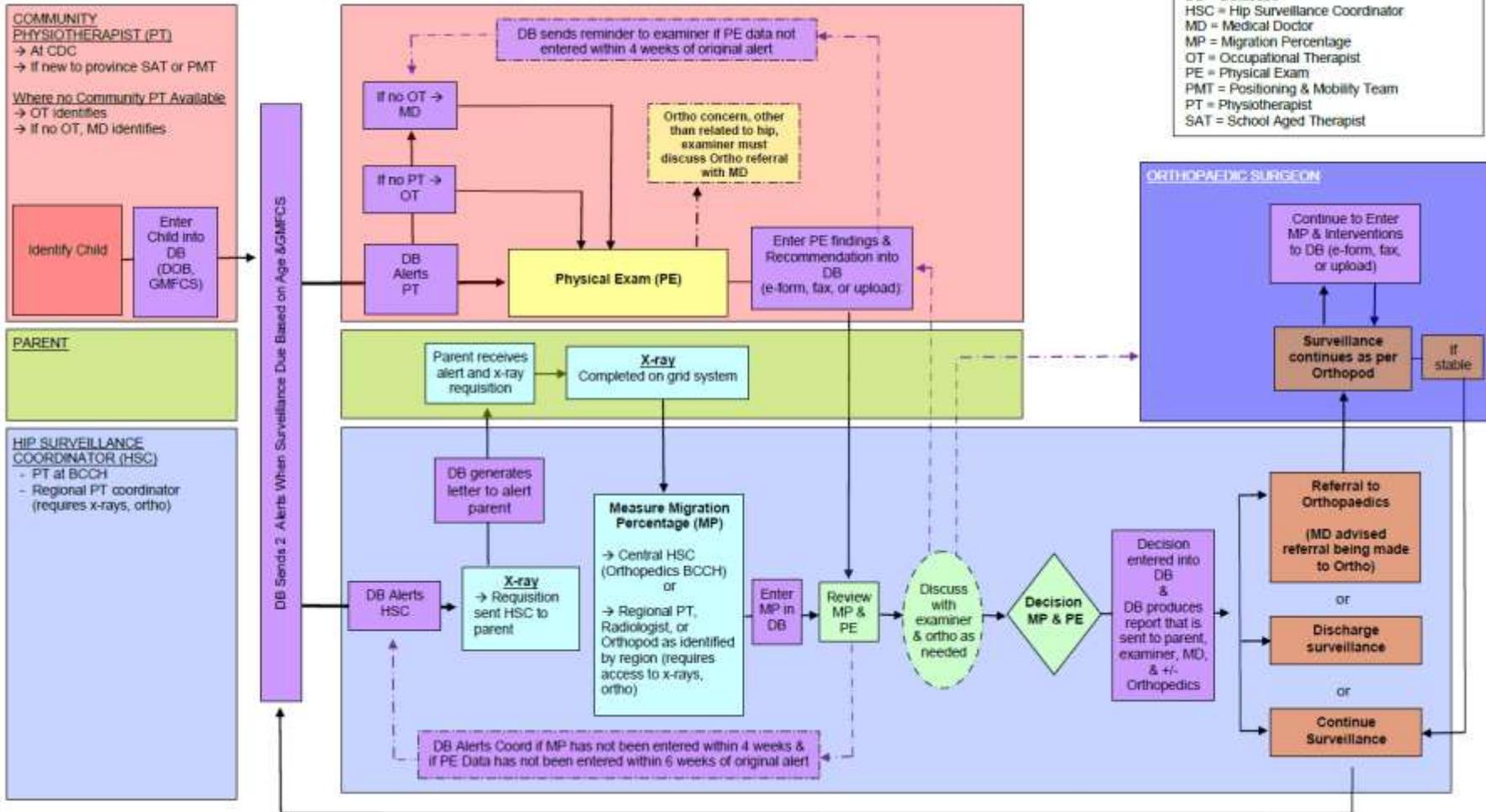


Figure 2

Model 2 Hip Surveillance Program: Program Coordination, No Database

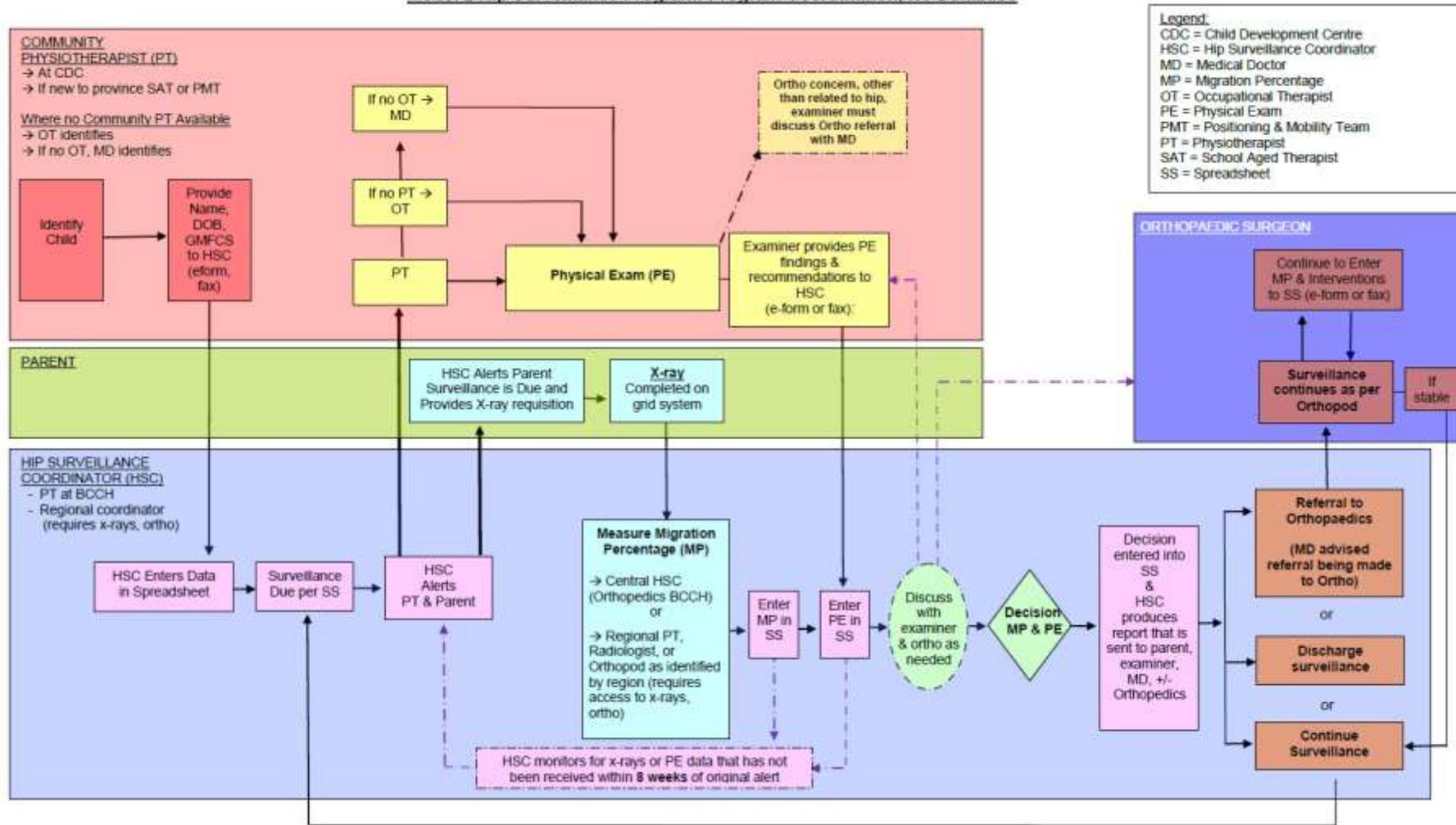


Figure 3

Model 3 Hip Surveillance Consensus Statement for Recommended Practice: No Program Coordination & No Database

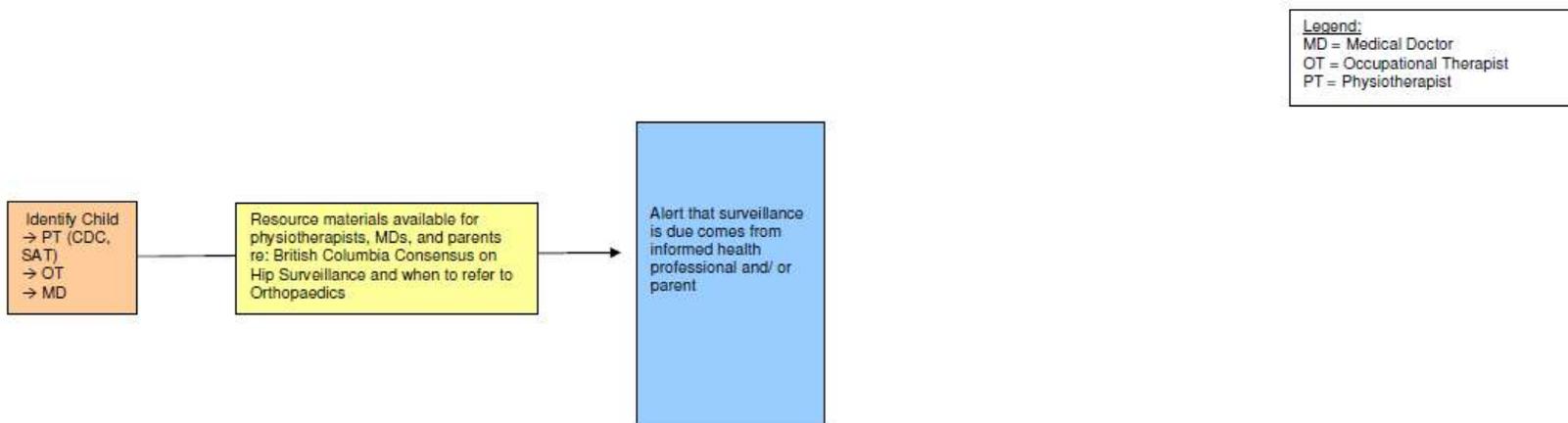
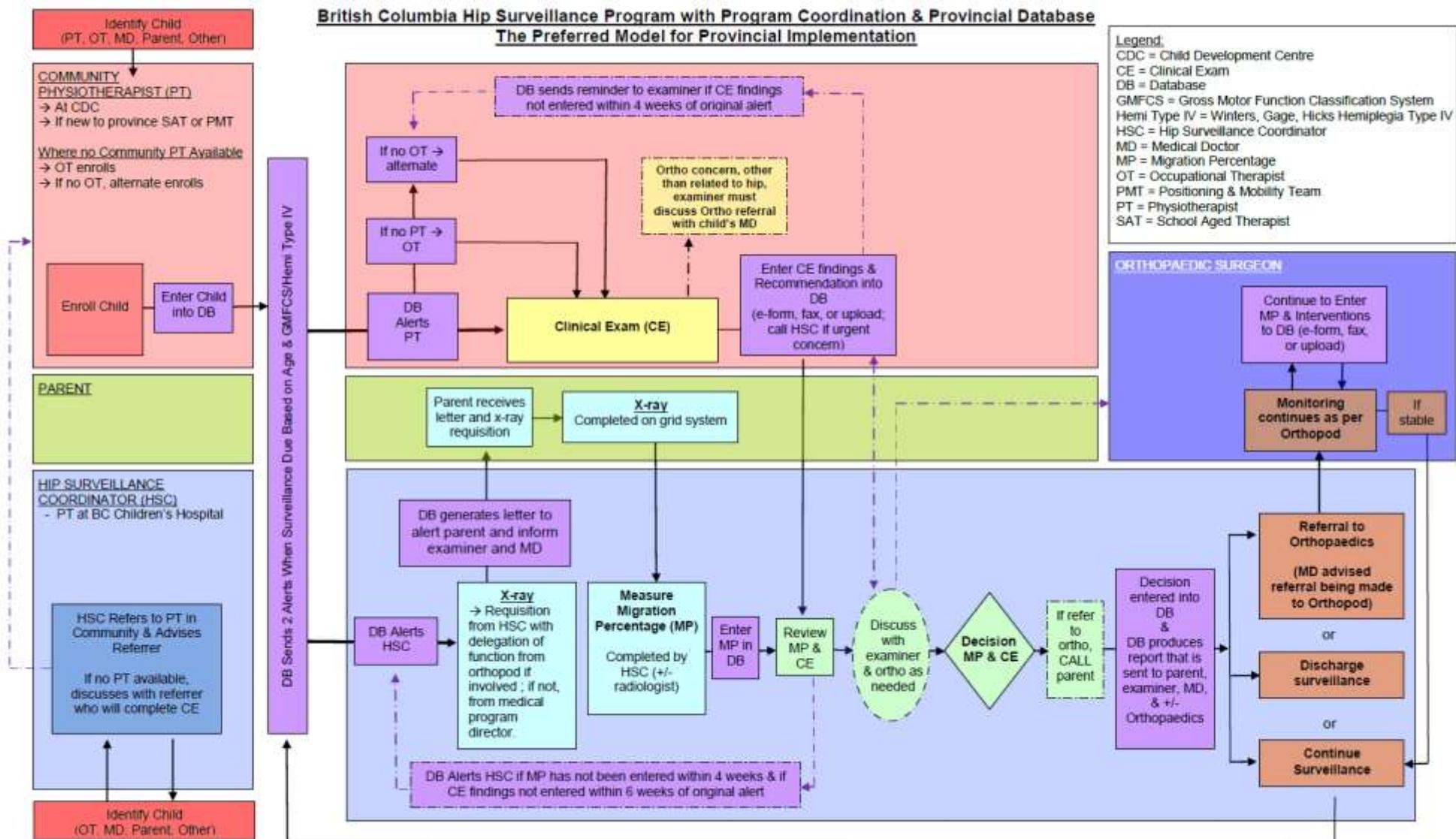


Figure 4



Knowledge Translation & Communications Plan: Possible Options for Parents, Clinicians & Technicians

Summary of Presentation by: *Tanja Mayson*

Knowledge translation (KT) is an essential component of implementing a BC hip surveillance program. KT is necessary to ensure families and health care professionals are aware of the Consensus Statement and that it is correctly implemented. Three topics relating to KT were discussed including KT considerations, KT methods, and KT content. Detailed content of this presentation is included in Appendix C.

The goals of KT are to impart the necessary knowledge and tools for successful implementation of hip surveillance to both parents and professionals and to generate:

- Awareness (Children/Parents and Professionals)
- Practice Change (Professionals)
- Behaviour Change (Children/Parents)
- System Change (Policy Makers and Funders)

It was recognized that regional and individual differences in KT needs and preferences may exist. The KT needs of those in remote locations, in aboriginal communities, and those who access services outside of their health region or province must be considered. Individual KT requirements are dependent on the individual's role in hip surveillance and their personal learning style. Financial considerations for KT development and maintenance were noted. Using available evidence, the most effective KT methods were identified. Methods with mixed and unknown effect were also reviewed.

Attendees were divided into regional sub-groups and participated in a discussion to address what information relating to the BC hip surveillance program needs to be communicated and to whom. How they would like to learn this information was also explored. A summary of the specific suggestions is included in Appendix C.

Evaluation

Summary of Presentation by: *Tanja Mayson and Stacey Miller*

The importance of evaluating the outcomes of a hip surveillance program was discussed. Consideration was given to which outcomes should be measured and when. Four areas were identified for evaluation and include:

- Effectiveness of knowledge translation
- Adherence to the Consensus Statement
- Patient and family outcomes
- The Consensus Statement

Evaluation of the effectiveness of the KT plan through assessment of reach indicators, such as website hits, and usefulness indicators was described for attendees. The evaluation of the adherence to the Consensus Statement, including completion of radiographs, positioning for radiographs, and reliability of clinical and radiographic measures, was identified as a potential use indicator for the effectiveness of KT.

The importance of patient and family outcomes, including satisfaction with the program, quality of life, and surgical interventions, was highlighted. Quality of life outcomes are currently being collected in the Department of Orthopaedics at BCCH, allowing for future comparison to the current experience of families.

The components of the hip surveillance program, including the frequency of radiographs and the Clinical Exam, require ongoing evaluation. Evaluation of the exam findings of children enrolled in the program will allow for the consideration of future changes to the Consensus Statement including the age of commencement of clinical exam and radiographs, components of the Clinical Exam, frequency of radiographs, and discharge from surveillance.

Attendees agreed that the BC Consensus Statement will be re-evaluated by the group in three years. Any questions or concerns that arise within the evaluation timeline will be discussed using tele-health conferences. Further details about the plan for evaluation can be found in Appendix D.

Conclusion

There is strong consensus that the treatment of hip displacement in children with CP in BC could be greatly improved. Implementing a comprehensive, coordinated approach to hip surveillance has the potential to positively impact the lives of children with CP and their families.

Hip dislocation is a common problem in children with CP and is associated with significant morbidity. Hip dislocation is, however, preventable through early identification and intervention. The creation of a provincial hip surveillance program will ensure that children are referred to a paediatric orthopaedic surgeon at the appropriate time.

During this meeting, important changes were made to the BC Consensus on Hip Surveillance for Children with Cerebral Palsy that was initially developed by the group in May 2010. These changes include consensus on:

- The definition for “similar conditions”
- The components of the Clinical Exam and Criteria for Referral to Orthopaedics
- Changing the age of the radiograph to age 5 rather than age 6 for children that are GMFCS Level I and II and have a Type IV gait pattern

A preferred model for hip surveillance was agreed upon by meeting attendees. There was unanimous agreement that a model for hip surveillance that includes a provincial coordinator and electronic data management system is needed to complete systematic surveillance and allow for well-timed intervention for hip displacement.

Knowledge translation (KT) and evaluation were identified as key components of an effective hip surveillance program; a preliminary plan for each was developed. The KT plan seeks to generate awareness, practice change, behavior change, and system change through the use of multiple methods. KT audiences, methods, and content were discussed. Evaluation in the areas of knowledge translation effectiveness, adherence to the Consensus Statement, patient and family outcomes, and the Consensus Statement were reviewed.

It was agreed that the Consensus Statement is due for review in three years.

Next Steps

Based on group discussion over the 1.5 day meeting, the group determined specific next steps that should be undertaken to implement the BC Consensus Statement on Hip Surveillance for Children with Cerebral Palsy.

Several items were identified as needing review following the meeting:

- Confirm how referrals for the BC mammography program work and how communication occurs within the program.
- Consider how we will be able to link with the CP registry research project in the future – a study collecting etiological information regarding children with CP in BC born after January 1, 2009.
- Consider how we will be able to link with databases currently in use in a large number of child development centers across the province.
- Investigate the best person to read migration percentage on x-ray: provincial coordinator or regional radiologist.

Ideas for short term implementation of the Consensus Statement were suggested:

- Have all of the pertinent information available online.
- Develop a communication plan.
- Identify health care professional groups who can get started with hip surveillance immediately.
- Create an information brochure for families which includes a time chart for scheduled examinations.
- Develop a teaching power point presentation for information dissemination.
- Create a detailed Clinical Exam form that is user-friendly and informative.
- Develop a spreadsheet examiners can download to begin tracking information.
- Investigate creating an x-ray requisition which includes an illustration demonstrating appropriate positioning for radiographic imaging and how to measure migration percentage.
- Set up a simple system to support short term data collection.
- Develop and communicate a press release for general awareness.

To achieve the above and ensure the long term success of this program in BC, a mechanism to seek and secure a provincial hip surveillance coordinator and establish a database, which together will ensure effective and consistent implementation of the Consensus Statement, is required.

Appendix A – Planning Committee and Attendees

Planning Committee Members (in alphabetical order)

No.	Name - Last	Name - First	Job Title	Hospital/Agency	City	Prov
1	Janice Duivestein, BSR, OT/PT, MRSc		Program Manager	Sunny Hill Health Centre for Children	Vancouver	BC
2	Nancy Lanphear, MD		Senior Medical Director	Sunny Hill Health Centre for Children	Vancouver	BC
3	Mary Lou Matthews, BEd, BSc, MSc		Manager, Child Health BC	Child Health BC	Vancouver	BC
4	Tanja Mayson, BSc(PT), MSc		Physiotherapist	Sunny Hill Health Centre for Children	Vancouver	BC
5	Stacey Miller, BSc(PT, Chem)		Physiotherapist	BC Children's Hospital	Vancouver	BC
6	Kishore Mulpuri, MBBS, MS (Ortho), MHSc (Epi)		Orthopaedic Surgeon	BC Children's Hospital	Vancouver	BC
7	Maureen O'Donnell, MD, MSc, FRCPC		Executive Director	Child Health BC	Vancouver	BC
8	Lori Roxborough, BSR, OT/OT, MSc		Therapy Associate Director & Outreach Manager	Sunny Hill Health Centre for Children	Vancouver	BC
9	Suzanne Steenburgh, BScN, MN		Program Manager	BC Children's Hospital	Vancouver	BC
10	Esias van Rensburg, MD, FRCPC		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/Other	City
1	Aird	Natalie	Peditrician	Vancouver Island Health Authority	Comox
2	Beare	Lisa	Recorder	HoweGroup	Vancouver
3	Beauchamp	Rick	Orthopaedic Surgeon	BC Children's Hospital	Vancouver
4	Begg	Jennifer	Nurse Navigator	Northern Health Authority	Prince George
5	Black	Alec	Director, Shriners Gait Lab	BC Children's Hospital	Vancouver
6	Boda	Lisa	District Physiotherapist	School District #60	Fort St. John
7	Boran	Sinead	Physician	BC Children's Hospital	Vancouver
8	Cameron	Dianne	Senior Director	Sunny Hill Health Centre for Children	Vancouver
9	Cox	Kim	Physiotherapist	FV CDC	Chilliwack
10	Duiveststein	Janice	Program Manager	Sunny Hill Health Centre for Children	Vancouver
11	Duncan	Jackie	Coordinator of Physiotherapy and Occupational Therapy Dept.	OSNS Child Development Centre	Pentiction
12	Elliott	Karol	Physical Therapist and Occupational Therapist	School District 23 Student Support Services	Kelowna
13	Evans	Janice	Section Head Physiotherapist	BC Children's Hospital	Vancouver
14	Fawdry	Brent	Director of Physiotherapy	Ridge Meadows CDC (MCFD funded)	Maple Ridge
15	Gentis	Michelle	Family Representative		Vancouver
16	Gibson	Audrey	Program Coordinator	Vancouver Island Health Authority	Victoria
17	Gillin	Shannon	Consultant, Child and Youth with Special Needs	Ministry of Children and Family Development	Vancouver
18	Gordon	Jason	Provincial Paediatric Therapy Recruitment and Retention Coordinator	Ministry of Children and Family Development	Kelowna
19	Gutter	Anneke	Physiotherapist	Powell River Association for Community Living	Powell River
20	Hesketh	Kim	Physiotherapist	BC Children's Hospital	Vancouver
21	Hilliard	Mike	physiotherapist	Vancouver Coastal Health	Vancouver
22	Hunter	Cynthia	Physiotherapist	Kamloops Children's Therapy & Family Resource Centre	Kamloops
23	Ivany	Cathy	Community Physiotherapist	Sea to Sky Community Services	Whistler
24	Johnson	Ruth	Network Director, Perinatal/Child Health Services, Medicine and Quality	Interior Health Authority	Vancouver
25	Jollet	Yvette	Chief Paramedical PT	Ministry of Children and Family Development	Abbotsford
26	Lake	Angela	Physiotherapist	Cariboo Chilcotin Child Development Centre	Williams Lake
27	MacLeod	Kim	Physiotherapist	Interior Health Authority	Kelowna
28	Masselink	W. Stephen	Physician	Vancouver Coastal Health	Vancouver
29	Matthews	Mary Lou	Manager, Child Health BC	Child Health BC	Vancouver
30	Mayson	Tanja	Physiotherapist	Sunny Hill Health Centre for Children	Vancouver
31	McAllister	Helen	Physiotherapist, TREKK Services - Elk Valley	Interior Health Authority	Fernie
32	McCaffrey	Janis	Physician	Vancouver Coastal Health	Vancouver
33	McIlwaine	Maggie	Professional Practice Leader	BC Children's Hospital	Vancouver
34	Meaning	Shirley	CYSN Therapy Manager	Ministry of Children and Family Development	Victoria
35	Miller	Stacey	Physiotherapist	BC Children's Hospital	Vancouver
36	Mulpuri	Kishore	Orthopaedic Surgeon	BC Children's Hospital	Vancouver
37	Newell	Veronica	Director of Physiotherapy	The Centre for Child Development	Surrey
38	North	Llaesa	Director of Physiotherapy	Child Development Centre of Prince George	Prince George
39	O'Donnell	Maureen	Executive Director	Child Health BC	Vancouver
40	O'Young	Daphne	Occupational Therapist	BC Children's Hospital	Vancouver
41	Penny	Norgrove	Orthopaedic Surgeon	Vancouver Island Health Authority	Victoria
42	Pirani	Shafique	Paediatric Othopaedic Surgeon	Fraser Health Authority	New Westminster
43	Pryce	Bonnie	Physiotherapist	Interior Health Authority	Kamloops
44	Roxborough	Lori	Therapy Assoc Director & Outreach Manager	Sunny Hill Health Centre for Children	Vancouver
45	Sims	Donna	Physiotherapist	Vancouver Island Health Authority	Victoria
46	Spence	Judit	Director of Physical Therapy	BC Centre for Ability-MCFD funded Early Intervention	Vancouver
47	Steenburgh	Suzanne	Program Manager	BC Children's Hospital	Vancouver
48	Strydom	Jaco	Family Physician	Northern Health Authority	Terrace
49	Swanson	Jane	Physiotherapist / Department Leader	Nanaimo Child Development Society	Nanaimo
50	Swartz	Erik	Head, Department of Pediatrics	Vancouver Coastal	Richmond
51	Symons	Shawna	Medical Radiation Technician	BC Children's Hospital	Vancouver
52	Therriault-Finke	Christine	Sole Charge Physiotherapist	Kootenay Family Place	Rossland
53	van Eeden	Christelle	Physiotherapist	Northern Health Authority	Delta
54	van Rensburg	Esias	Developmental Pediatrician	Sunny Hill Health Centre for Children	Vancouver
55	Warcup	Margaret	Executive Director	Northern Health Authority	Kitimat
56	Wickenheiser	Diane	Project Coordinator, Canadian Cerebral Palsy Registry - BC Division	BC Children's Hospital	Vancouver
57	Willms	Brenda	Orthopedic Nurse Clinician	BC Children's Hospital	

Appendix B – Discussion of Possible Models

Summary of Discussion Points from Participants - Key Questions for Implementation

(Please note that this section reflects participant comments but not group consensus).

1. Who can / should identify the child?

- Anyone involved with the child can identify them.
- Answers given: Physiotherapist (PT), medical doctor (MD), including general practitioner (GP) and pediatrician, occupational therapist (OT), public health nurse (PHN), Infant Development Program (IDP) consultant, nurse practitioner (NP), Special Care Nursery (SCN), Early Intervention Therapy (EIT), social worker (SW) and parent.
- They just need to know where to direct the child.
- It is mainly Early Intervention therapists who are identifying children with CP.
- The issue of identification vs. enrollment was debated; there may need to be an extra step created concerning who enrolls the child.
- We need to err on the side of seeing more children so that we don't let them slip through the cracks.

In response to the discussion during the first day, Question 1 was divided into three parts.

1a: Who will identify the child?

- Anyone can identify these children. Add everyone to the above list to allow greater chance of entry to the program.
- Success is all about finding the kids.

1b. Who will enroll the child?

- Change to: Who will screen and enroll the child.
- Word 'screening' is better for parents than 'surveillance'.
- Screening means they have CP or similar conditions.
- Possibility of sending all applications for enrollment through the Provincial Coordinator to review. There would initially be a large number of applications, which would then even out as the program progresses.

1c. Who will complete the clinical exam?

- Answers given: PTs, Developmental Paediatricians, Neurologists, EIT PT, School Aged Therapists (SAT) PT, OT, MD, arranged through hip surveillance coordinator (HSC).
- If no PT we would rather a MD or OT. Often schools have an OT associated with them.
- There will need to be training for measurements.
- It is most important to identify the children and the people who can identify them.
- Private PTs are paid on a fee for service basis so cannot be expected to complete the clinical exam.

This question developed into a lengthy debate concerning at what age GMFCS I and II receives x-rays. Age 5 or 6? When dealing with GMFCS I and II the x-ray is needed to ensure they are not missed. It would be easier if the age changed to 5, as that is how our provincial school system works. Therapists who have a history with the children up until age 5 would have less variability than school therapists that take over at age 6. There is a fear that if a child is discharged early from an early intervention program they could get missed. However the database would be age based so as long as the child is in the system they would be identified and alerted for x-rays.

GMFCS I and II: Should we change the age of radiograph to 5 years of age? This would still involve the same number of x-rays but the initial x-ray would be completed 1 year earlier.

Why was it 6 years to begin with?

- Swedish model is age 6
- Consistent with age used for GMFCS III, IV, V. ('every 6 months till 6 years' for GMFCS IV and V)

- Australia all children get an x-ray at identification and again at age 5. We've left out that initial x-ray at identification of CP for GMFCS I and II. But an x-ray can be ordered at anytime if the clinical exam raises concerns.

If we change GMFCS I and II to age 5 would we also change Hemi Type IV?

- This would give them one extra x-ray in their life.
- There would be less of a risk of them falling off surveillance once early intervention ends.
- They are more at risk so the extra monitoring would only be beneficial.

Consensus achieved: Children with GMFCS I and II will get their radiograph at age 5.

Consensus achieved: Children with Hemi IV will get their radiograph at age 5.

Should we change GMFCS III, IV and V to age 5 as well?

- With age 5 there could be annual x-rays instead of every 6 months
- Symmetry between all systems would be easier
- These children could have rapidly changing conditions which is dangerous if they lose out on exams

In a show of hands in favor of changing GMFCS I and II to age 5 and keeping GMFCS III, IV, and V at age 6, the room was evenly split. Further discussion occurred about changing the age of first x-ray for GMFCS III, IV, and V.

Consensus achieved: GMFCS III, IV and V will remain that same at age 6.

2. Who can/ should manage surveillance?

Following possibilities presented:

- Provincial Coordinator (could also be called Central Coordinator or Hip Surveillance Coordinator (HSC))
- Provincial Coordinator in conjunction with Regional Coordinator
- Provincial Coordinator to start and see if the need for Regional Coordinators arise

Regional Coordinators do not necessarily have to be coordinator, they could be a regional contact designated to assist with community liaisons. Use of a Regional Contact under the Provincial Coordinator is preferred over a Regional Coordinator for ease of implementation. Surgeons could benefit from Regional Contacts (RCs) and could allow them to requisition x-rays for their specific children. RCs could try and link with doctors who travel in remote areas once a year. Discussion with families should happen at a regional level when available. However, surgeons agree that is easier to have a HSC contact them vs. multiple PTs or RCs. Many children already have surgeons attached to them. Regional Contact is more about education, monitor quality, work with PT, leadership and management of region.

Regional coordination requires adequate volume to maintain expertise. We will not be able to offer the same level of service all over the province due to volumes. Tiers of service that are available locally vary by region.

- Tier 1. General Providers i.e. GPs, Teachers.
- Tier 2. Community Level Providers focused on children or Pediatric PTs.
- Tier 3. Regional Multi Disciplinary Team focused on a specific region.
- Tier 4. Provincial one of a kind service. They need to be provincial due to rarity and low volume. Multi sub specialty teams or technicians. Orthopaedic interventions may have some specific requirements for a Tier 3 or 4 team.

Concern that regions should not necessarily be divided by health authority as many authorities already have natural regional divides within them. Possible multi sectorial division could be an overlay combining the Health Authorities, MCFD, and School Districts.

Consensus was achieved that the program should begin with a Provincial Coordinator and potentially implement Regional Contacts as needed.

3. Is a database required?

There was unanimous consensus that a database is required. There is understanding that this will take time. There is the possibility of step method implementation. Ideally the Hip Surveillance Program will become one part of a whole larger system for children with CP.

4. Who can / should request a radiograph?

Answers given: HSC, Physiatrist, Orthopod, MD with prompting from PT, Paediatrician, Medical Director attached to the program, and generated from database.

There was interest in having a requisition automatically generated without a signing requirement. A letter would be sent to the parents with the x-ray requisition. If the child is already seeing an Orthopaedic Surgeon then the requisition should come from them. If there is a regional Ortho their signature could be used. There was discussion about how Mammography screening works in BC? There is no need to return to your GP, you simply go in for the next scheduled x-ray on the time chart. Could the same requisition for imaging and monitoring system be used for hip surveillance?

Surgeons agree that if they order an x-ray then they are responsible for following up on the results. Many children that are GMFCS III, IV and V are already seen by a surgeon. Surgeons will generally take a referral from anyone and notify the family GP associated with the child. We asked the three surgeons in the room whether would want to sign the requisitions themselves vs. a coordinator or medical director of the hip surveillance program. They all agreed they want to sign themselves and be given scheduled alerts from the coordinator.

Attendees agree that children enrolled in the program are often linked with a family physician and therefore may already come with x-rays. Once referred to a specialist, families often return to the family physician with questions. Primary care physicians will need to be involved and will usually be the port of entry.

There is possibility of sending an automatically generated letter to the families and their doctors so that the GP can generate the requisition right then. Most GPs would order it without seeing the child in their office (removing an extra step), if the child is already enrolled in the program. If there is no link with a GP or Surgeon then the HSC will be vitally important for contact.

- Some hospitals refuse to use any requisition forms other than their own.
- Family doctors are changed frequently so mass mail out may not work. Many families use walk in clinics. Timely requisition from family physician is not realistic.

It was identified that the role of the family physician in the model needed to be clarified:

- What is the role of GP or Paediatrician? They aren't even notified till end of flow. Needs to happen immediately once their children are identified in the database. Doctors may then take an interest.
- Flag the most responsible doctor immediately upon entry in the program. Add this to the Clinical Exam so it is being updated regularly.

There was consensus that x-rays should be requested by the provincial coordinator with delegation of function from orthopaedic surgeon.

- If no orthopaedic surgeon is involved, radiograph request with delegation of function from medical program director
- Family physicians, paediatricians and person completing clinical exam will be informed when radiograph request is sent to the parent
- During clinical exam, clarify which physicians are involved in care to assist with disseminating hip surveillance findings to appropriate care providers

5. *Who can / should measure MP?*

Answers given:

- Paediatric Orthoped
- Hip Surveillance coordinator
- All community radiologists
- Designating specific Radiologists

The following points were brought up for discussion:

Designating specific radiologist could possibly disrupt radiology referral practices in the region.

X-ray may have to be read twice, may not be cost effective to have them read centrally.

- Training will have to be done for all options.
- HSC could collate the results.

How will we educate radiologists?

- Not sure yet. They are a big group of people. Need a partner from Children's Hospital.

Who will inform families of the results?

- Options are provincial coordinator or local PT (who enrolled the child)
- Loss of knowledge if information is passed from coordinator to local PT
- PT can talk about the whole picture with the family
- Discussion leaned towards the HSC calling with results. No decision achieved.

Appendix C – Determining Knowledge Translation Needs and Preferences

Summary of Presentation:

Knowledge Transfer Considerations	Knowledge Transfer Methods	Knowledge Transfer Content
<p>Audiences</p> <ul style="list-style-type: none"> • Parents • Children • Physical therapists • Occupational therapists • Nurses • Infant Development Consultants • Orthopaedic Surgeons • Family Physicians • Paediatricians • Radiologists • Radiology Technicians • Policy Makers • Funders <p>Regional Needs and Preferences</p> <ul style="list-style-type: none"> • Five health regions • Provincial health services • Remote areas within health regions • Aboriginal communities • Families accessing out-of-province services • Families accessing out-of-region services <p>Individual needs and Preferences</p> <ul style="list-style-type: none"> • Role in hip surveillance program • Time • Learning styles & preferences for accessing information <p>Financial Cost</p> <ul style="list-style-type: none"> • Initial KT <ul style="list-style-type: none"> ○ Developing KT resources ○ Actual KT method ○ Time for individuals to learn • Maintaining KT • Training person new to role 	<p>Most Effective</p> <ul style="list-style-type: none"> • Interactive small group • Educational outreach • Audit/feedback • Reminders (email, fax) <p>Mixed Effects</p> <ul style="list-style-type: none"> • Conferences/courses <ul style="list-style-type: none"> ○ Live (in-person or webcast or teleconference) ○ Viewed after fact (weblink or YouTube) • Knowledge brokers • Educational materials <ul style="list-style-type: none"> ○ Posters ○ Pamphlets ○ Newsletter articles ○ Website • Peer reviewed publications <p>Unknown Effects</p> <ul style="list-style-type: none"> • Apps • Social Media • Networks • Communities of Practice • Discussion with Peers • QR code on printed materials • Messenger <ul style="list-style-type: none"> ○ Same role peer ○ Any role peer 	<p>Evidence for hip surveillance</p> <p>Importance of hip surveillance</p> <p>Surveillance inclusion criteria</p> <ul style="list-style-type: none"> • CP • Similar conditions <p>Classification</p> <ul style="list-style-type: none"> • GMFCS • Hemiplegia Type IV <p>Clinical Exam</p> <ul style="list-style-type: none"> • Frequency • Content • How to complete items <p>Radiographs</p> <ul style="list-style-type: none"> • Frequency • Positioning • Measuring migration percentage <p>When to Refer to Orthopaedics</p> <ul style="list-style-type: none"> • Criteria <p>Program Process</p> <ul style="list-style-type: none"> • What to expect • Communication <ul style="list-style-type: none"> ○ Alerts ○ Findings

Question for Small Group Discussion:

For your region, please consider what information each of the following groups requires regarding the BC hip surveillance program and how they would like to receive this information?

- Families
- Physiotherapists
- Occupational therapists
- Public health nurses and other nurses
- Family physicians
- Paediatricians
- Psychiatrists
- Orthopaedic surgeons
- Radiologists
- Radiation technologists

Summary of Small-Group Discussion by Audience: *(Please note that this section reflects participant comments but not group consensus).*

Parents/Children	PT, OT	PHN, NP, IDP	GP, Pediatricians, Physiatrists	Orthopaedic Surgeons	Radiologists, Radiation Technicians
<p>Make information available that is in a format families can easily understand</p> <p>Include references to further education if the parent is interested</p> <p>Be mindful of families with English as a second language</p> <p>Create a card or chart schedule similar to immunization system to include with a parent booklet</p> <p>Create a card or a chart detailing the parents role within the system</p> <p>Divide information between GMFCS I & II and GMFCS III, IV & V so not to overwhelm families</p> <p>Include further contact information</p>	<p>Best if it comes from another PT</p> <p>The online learning modules would be great</p> <p>Create a specific form for the Clinical Exam that is easy to complete – simple explanations given with standardization information and diagrams</p> <p>When creating programs to educate medical personnel, a broad program can be created with chapters created for each specific group</p> <p>Bring in the private sector physiotherapists as they are part of this group</p> <p>Use Pediatric Council mailing lists and annual meetings</p> <p>Include in PT professional training curriculum</p> <p>Offer training course at universities</p> <p>Regional knowledge brokers</p>	<p>Need an understanding of what the program is</p> <p>Referral to local physiotherapist if available. If not contact hip surveillance coordinator</p> <p>Use knowledge brokers</p> <p>Add materials with the logistics of the program</p>	<p>Similar to other professionals</p> <p>Publish articles</p> <p>CME event presentations</p> <p>Peer to peer best</p> <p>Create an info page to include with x-ray requisitions</p> <p>Information regarding specific role of physicians</p> <p>Make sure to capture right group for CME</p> <p>BCMJ has theme issues and could possibly have a CP issue</p> <p>Set up a standardized power point presentation to ensure the same message is being passed on a local level</p>	<p>Have a 2 day program every year that we could speak at</p> <p>Must ensure to include surgeons on the Alberta/BC border as well as some in Washington and Oregon</p>	<p>Department heads need to be on board to champion the program</p> <p>Targeted training</p> <p>Peer to peer</p> <p>Billing incentive to measure migration percentage</p> <p>Weekly email journal available</p> <p>Web based learning with lots of images of how to correctly position and measure</p> <p>Certain regions may not have required equipment or tools available</p> <p>Create a visual document to go with requisition with positioning and measuring instructions</p>

Appendix D – Evaluation

Summary of Presentation:

Evaluation Methods

1. Effectiveness of Knowledge Translation

- Reach indicators
 - Copies distributed
 - Copies requested
 - Number of downloads
 - Number of hits
- Usefulness indicators
 - Satisfaction with materials
 - View changed after KT

2. Adherence to consensus statement and quality control

- Also a 'use indicator' of effectiveness of KT- Measure expected vs. actual number of completed radiographs and clinical exams in specified period of time
- Verify adherence to proper positioning
- Verify reliability of clinical exam
 - Intra-rater reliability & Inter-rater reliability
- Verify reliability of MP measurement
 - Intra-rater reliability & Inter-rater reliability

3. Patient and family outcomes

- Satisfaction and family outcomes
- QOL outcomes using CPCHILD verses current treatment group (currently collecting)

4. Radiological

- Robin and Graham Hip Classification System for Hip Disease (radiographic classification bases on gross morphological features and MP)
- Hip displacement and scoliosis

5. Evaluation of Consensus as a Whole

- Radiological
 - Detection rates by GMFCS using MP
 - Age at presentation (are we x-raying at the correct time)
 - Rate of progression while on surveillance (are we x-raying often enough or too often)
- Clinical Exam
 - Are the measures being used in decision making?

6. Interventions: Surgical and Non-Surgical

- Number progressing to intervention
- Types of intervention required
- Effectiveness of intervention by GMFCS level
 - Effect on MP
- Complications related to interventions



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