CHILD HEALTH BC HIP SURVEILLANCE PROGRAM for Children with Cerebral Palsy

Child Health BC Hip Surveillance Program: Successes & Challenges from Our First 3 Years

Provincial Health Services Authority Province-wide solutions. Better health.

CHILD HEALTH BC LEAD BENEFACTOR save on foods

BC Children's Hospital

UBC THE UNIVERSITY OF BRITISH COLUMBIA

Stacey Miller, BSc (PT), MRSc

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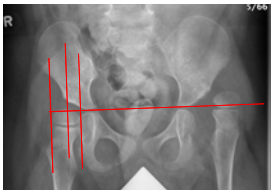
Objectives

- To review the current enrollment in the Child Health BC Hip Surveillance Program for Children with CP and compare enrollment by age, GMFCS, and region.
- To describe results of a 2017 BC therapist survey identifying barriers to enrollment and the program's strategies to overcome these barriers.
- To provide results of a survey of BC pediatricians related to CP and diagnoses.

Hip Displacement

- Gradual lateral movement of the femoral head from under the acetabulum

Normal hip alignment

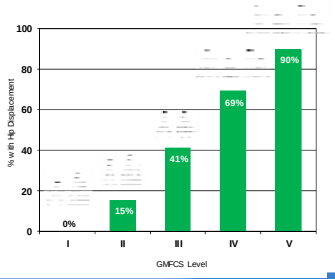


Hip displacement & dislocation



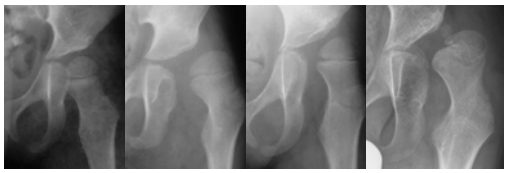
1 in 3 children with CP have hip displacement

Risk for Hip Displacement



Soo et al., 2006; Illustrations Version 2; Reid B, et al. The Royal Children's Hospital, Melbourne, Australia.

Consequences



Pain
Decreased quality of life
Loss of mobility
Loss of ROM
More complex surgery

Hip pain is more frequent in severe hip displacement: a population-based study of 77 children with cerebral palsy

Kjersti Ramstad[a] and Terje Terjesen[b] J Pediatr Orthop B. 2016 May;25(3):217-21.

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

Hip health at skeletal maturity: a population-based study of young adults with cerebral palsy

JOANNA WYNNZUTA[1,2] | KATE L WILLOUGHBY[3,4] | CHARLOTTE MOLESWORTH[4] | SOON GHEE ANG[1] | BENJAMIN J SHORE[5] | PAM THOMASON[5,6] | H KERR GRAHAM[1,2,3,4]

Characteristics of Pain in Children and Youth With Cerebral Palsy

www.pediatrics.org/cgi/doi/10.1542/peds.2013-0224

AUTHORS: Melanie Penner, MD, FRCPC,[a,b] Wen Yan Xie, BMSc,[a] Navneet Binepal, MD,[a] Lauren Switzer, MSc,[b] and Darcy Fehlings, MD, MSc, FRCPC[a,b]

[a]Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada; and [b]Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario, Canada

Acta Orthopaedica 2017; 88 (2): 205–210

Severe hip displacement reduces health-related quality of life in children with cerebral palsy

A population-based study of 67 children

Kjersti RAMSTAD [1], Reidun B JAHNSEN [1], and Terje TERJESEN [2]

DEVELOPMENTAL NEUROREHABILITATION

http://informahealthcare.com/pdr
ISSN: 1751-8423 (print), 1751-8431 (electronic)

informa healthcare

ORIGINAL ARTICLE

Does hip displacement influence health-related quality of life in children with cerebral palsy?

Nikolai H. Jung[1], Barbara Pereira[1,2], Ina Nehring[1,3], Olga Brix[4], Peter Bernius[5], Sebastian A. Schroeder[4], Gerhard J. Kluger[6], Tillmann Koehler[1], Andreas Beyerlein[7], Shannon Wei[7], Rüdiger von Kries[1], Unni G. Narayanan[8], Steffen Berweck[4,9,*] & Volker Mall[1,*]

Treatment

Depends on:

- The extent of hip displacement
- Secondary bony changes
- Pain
- Age
- The child and family

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY SYSTEMATIC REVIEW

Prevention of hip displacement in children with cerebral palsy: a systematic review

STACEY D MILLER[1] | MARIA JURICIC[1] | KIM HESKETH[2] | LYNDRE MCLEAN[3] | SONJA MAGNUSON[1] | SHERYLIN GASIOR[3] | EMILY SCHAEFFER[1,4] | MAUREEN O'DONNELL[3,5] | KISHORE MULPURI[1,4]

1 BC Children's Hospital, Vancouver, BC, 2 Closing the Gap Health Care Group, Barrie, ON, 3 Sunny Hill Health Centre for Children, Vancouver, BC, 4 Department of Orthopaedics, University of British Columbia, Vancouver, BC, 5 Department of Pediatrics, University of British Columbia, Vancouver, BC, Canada

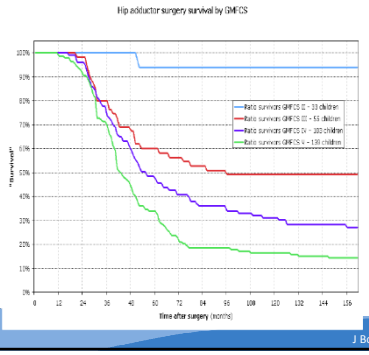
Dev Med Child Neurol. 2017 Nov;59(11):1130-1138.

- Botulinum toxin ±bracing(6), complementary & alternative medicine(1), intrathecal baclofen(1), obturator nerve block(1), positioning(8), selective dorsal rhizotomy(7)
- Conclusion: Insufficient evidence to support or refute the use of the identified interventions

Surgical Intervention: "Preventive"

Soft-tissue release

- Adductor longus release
- Gracilis release
- Adductor brevis release
- Iliopsoas lengthening
- Obturator neurectomy



Success:
No subsequent surgery, MP < 50%

GMFCS level II: 94%

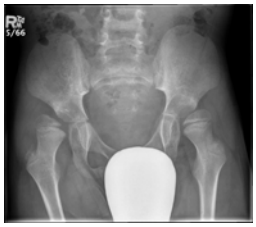
GMFCS level III: 49%

GMFCS level: 27%

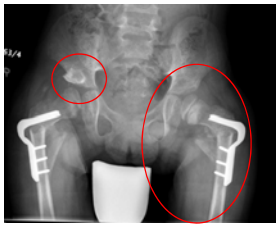
GMFCS level: 14%

J Bone Joint Surg Am. 2012 Feb 15;94(4):326-34

Surgical Intervention: Reconstruction



Pre-operative



Post-op: Bilateral varus derotation osteotomies and right pelvic oblquity

Effect of Hip Reconstructive Surgery on Health-Related Quality of Life of Non-Ambulatory Children with Cerebral Palsy

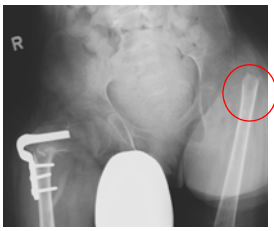
Rachel DiFazio, PhD, RN, PPCNP-BC, FAAN, Benjamin Shore, MD, MPH, FRCSC, Judith A. Vessey, PhD, MBA, RN, FAAN, Patricia E. Miller, MS, and Brian D. Snyder, MD, PhD

Investigation performed at Boston Children's Hospital, Boston, Massachusetts

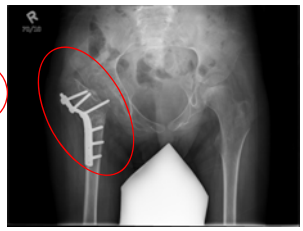
J Bone Joint Surg Am. 2016;98:1190-8

- Pre-op: higher MP associated with decreased HRQOL
- Post-op: lower MP associated with increased HRQOL

Surgical Intervention: Salvage Procedure



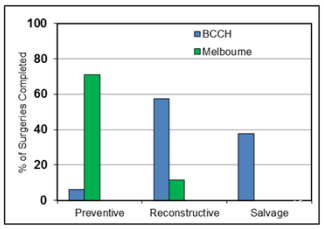
Femoral head resection



Femoral head resection and valgus osteotomy

The BC Experience: A Need for Change

- Chart audit of an 18 month period at BC Children's Hospital (BCCH) in 2008 and 2009
  - >1/3 of hip surgeries performed were salvage procedures for painful dislocated hips

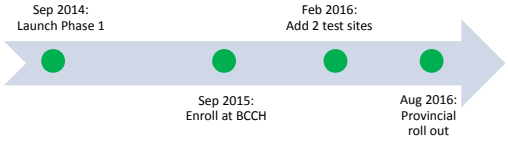


Hip Surveillance

Early detection =
Treatment options remain open

Surgical intervention, prior to dislocation, is recommended to keep the hip in joint, mobile, and pain free

Provincial Roll Out



Child Health BC Hip Surveillance Program

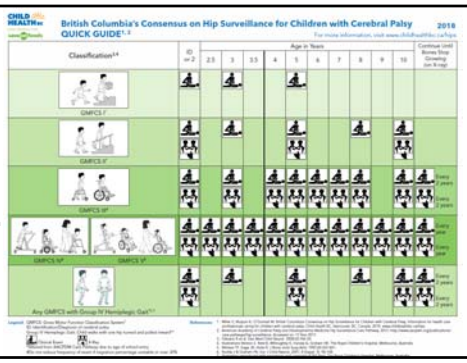
Child Development Centers

School Services

Pediatric Orthopaedic Surgeons

Hip Surveillance Coordinator/Medical Lead

BC's Consensus was updated in 2018 to reflect international consensus gained during the creation of the American Academy of Cerebral Palsy and Development Medicine (AACPDM) Hip Surveillance Care Pathway.



BC's Clinical Exam

- GMFCS level (MACS/CFCS)
- Motor distribution
- Group IV Hemiplegic Gait (unilateral CP)
- Motor type
- Hip abduction in extension
- Question re: pain
- Pain on clinical exam

*BC's clinical exam components were updated in 2018 to reflect international consensus gained during the creation of the AACPDM Hip Surveillance Care Pathway.

Radiological Exam

- AP pelvis (supine)
- Measure Migration Percentage (MP)
- Positioning
  - Abduction/adduction: Neutral
  - Hip rotation: Patellae up
  - Neutral Pelvic Obliquity; Flattened lordosis

Referral to Orthopaedics

- Migration Percentage > 30%
- End of range hip abduction < 30˚ (hips at 0º flexion and knees extended)
- Pain on clinical exam
- Pain on parent report
- Any other clinical concern that is felt to be related to the hip

SURVEY SAYS….

Knowledge & Needs Surveys

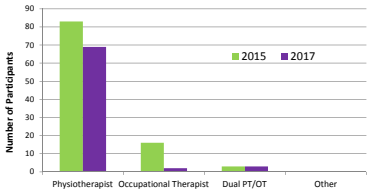
Surveyed pediatric PTs/OTs in BC in 2015 to:
- Determine knowledge related to CP & hip displacement
- Learning needs and wishes

Repeated survey in 2017 to:
- Re-assess knowledge
- Determine satisfaction with initial rollout and enrollment process

Pediatrician survey in 2018:
- Determine knowledge related to CP & hip displacement
- Learning needs and wishes

Therapist Survey Results 2015/2017

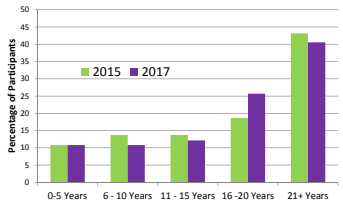
What is your discipline?



2015: Physiotherapist (83%), Occupational therapist (16), Dual PT/OT (3), Other (0) = **102 responses**
2017: Physiotherapist (69), Occupational therapist (2), Dual PT/OT (3), Other (0) = **74 responses**

Therapist Survey Results 2015/2017

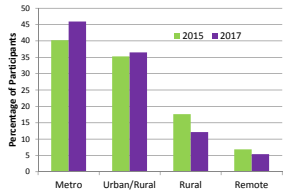
Please indicate your years of clinical experience:



2015 : 0-5 Years (11), 6-10 years (14), 11-15 years (14), 16-20 years (19), 21+ years (44) = 102
2017: 0-5 Years (8), 6-10 years (8), 11-15 years (9), 16-20 years (19), 21+ years (30) = 74

Therapist Survey Results 2015/2017

Which best describes your practice setting?

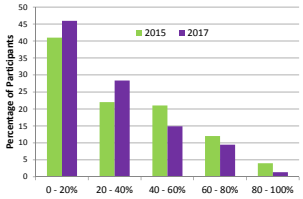


Population:
Metro: Over 190,001
Urban/Rural: 40,001 - 190,000
Rural: 10,001 - 40,000
Remote: 0 - 10,000

2015: Metro (41), Urban/Rural (36), Rural (18), Remote (7) = 102
2017: Metro (34), Urban/Rural (27), Rural (9), Remote (4) = 74

Therapist Survey Results 2015/2017

What percentage of your paediatric caseload consists of children with CP or CP like conditions?



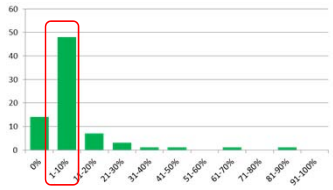
2015: 0-20% (41), 21-40% (22), 41-60% (21), 61-80% (12), 81-100% (4) = 100
2017: 0-20% (34), 21-40% (21), 41-60% (11), 61-80% (7), 81-100% (1) = 74

2018 Pediatrician Survey

- 78 Responses
- 46 (60.5%) General Pediatricians
- Practice Setting:
  - 62% Metro (pop over 190,001)
  - 29% Urban/Rural (pop between 40,001-190,000
  - 8% Rural (pop 10,001-40, 000)
  - 1% Remote (pop < 10,000)

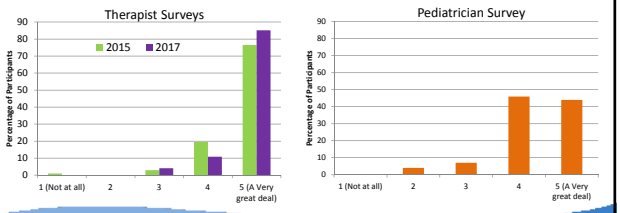
2018 Pediatrician Survey

Please estimate the percentage of the children in your practice who have cerebral palsy.



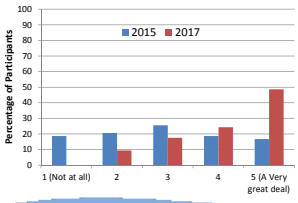
Question re: Support for Surveillance

I think hip displacement in children with CP is a problem that requires standardized monitoring.

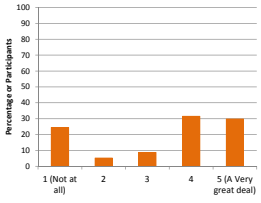


Question re: Familiarity with Program

I am familiar with the BC Consensus Statement on Hip Surveillance for Children with CP.

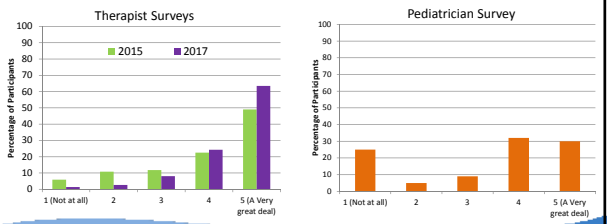


I am familiar with the Child Health BC Hip Surveillance Program for Children with Cerebral Palsy.



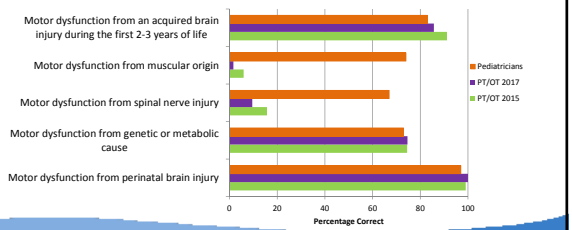
Question re: Use of GMFCS

I identify Gross Motor Function Classification System (GMFCS) levels for all of my clients with CP

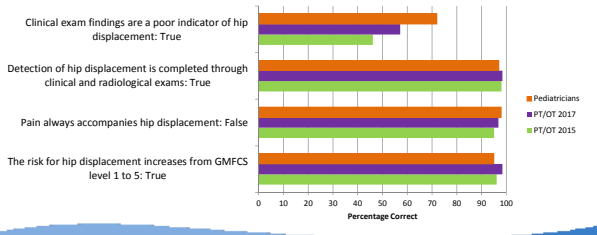


Questions re: Cause of CP

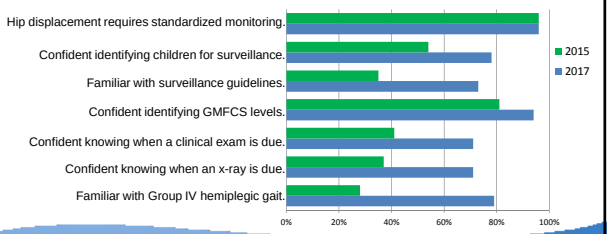
Which of the following underlying causes of motor impairment can result in cerebral palsy? Please check all that apply.



Questions re: Hip Displacement

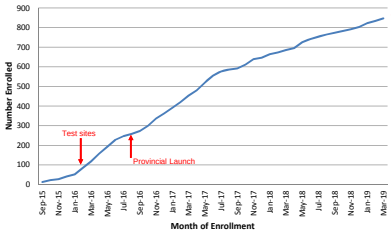


2017 Therapist Survey



CURRENT ENROLLMENT

Current State

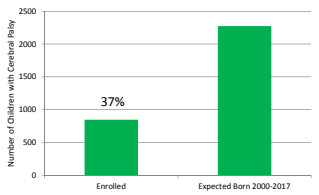


847

370 Female
477 Male

Enrollment to March 31, 2019

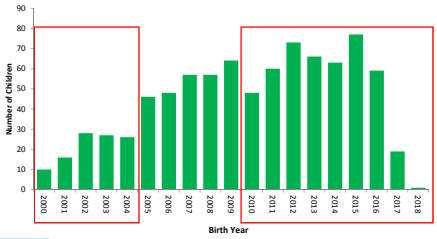
Enrollment vs Expected



*based on a prevalence rate of 2.68 per 1000

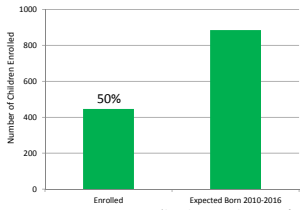
Enrollment to March 31, 2019

Enrollment by Birth Year



Enrollment to March 31, 2019

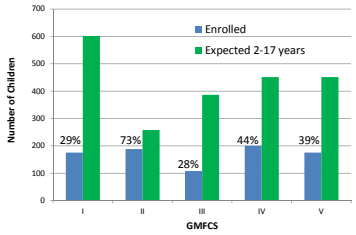
Enrollment vs Expected



*based on a prevalence rate of 2.68 per 1000

Enrollment to March 31, 2019

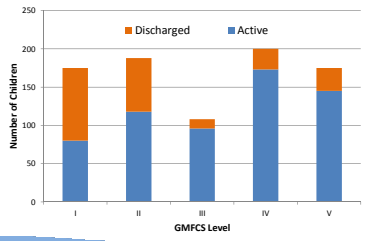
Enrollment by GMFCS



Enrollment to March 31, 2019

Dev Med Child Neurol. 2008; 46: 461-467

Discharged By GMFCS



28% (234) Discharged

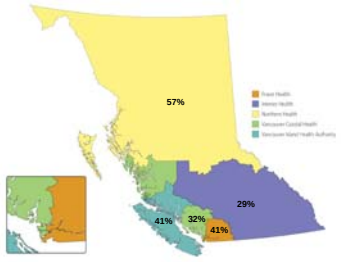
Enrollment to March 31, 2019

Discharged From Surveillance

Level I/II with acceptable x-ray	147
Skeletal Maturity with acceptable x-ray	46
Deceased	12
Level I, no x-ray	8
Dislocated, reconstruction not possible	7
Moved	7
Intervention not medically recommended	2
Other	5

Enrollment to March 31, 2019

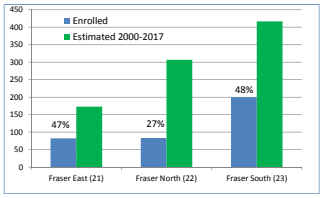
Enrollment by Region



Enrollment to March 31, 2019

Enrollment by Region: Fraser

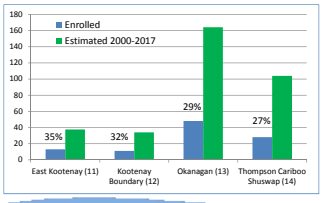
2018 = 33% 2019 = 41%



Enrollment to March 31, 2019

Enrollment by Region: Interior

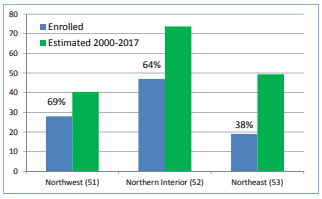
2018 = 20% 2019 = 29%



Enrollment to March 31, 2019

Enrollment by Region: North

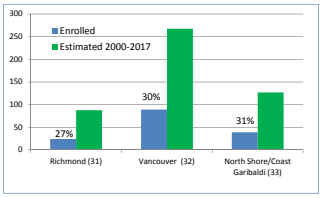
2018 = 47% 2019 = 57%



Enrollment to March 31, 2019

Enrollment by Region: Vancouver Coastal

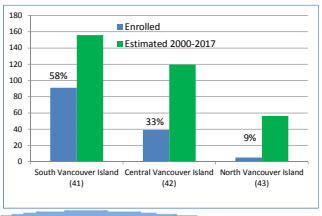
2018 = 27% 2019 = 32%



Enrollment to March 31, 2019

Enrollment by Region: Vancouver Island

2018 = 39% 2019 = 41%

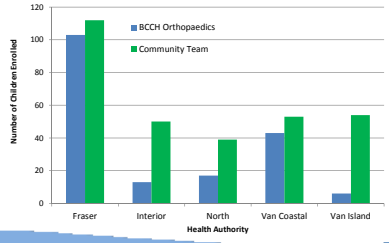


Enrollment to March 31, 2019

Current State: Enrolling Clinicians

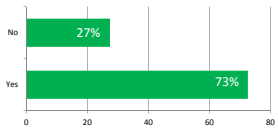
- 52% (440) enrolled by child's community team (PT, OT, physician)
- 122 different referring providers (PT, OT, pediatricians)

Enrollment by Provider: 2017-19

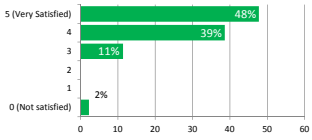


2017 Therapist Survey

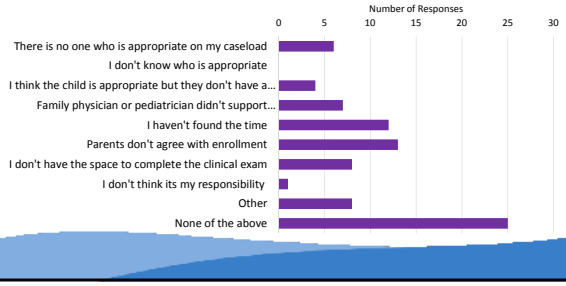
Have you enrolled a child in the CHBC Hip Surveillance Program?



How satisfied are you with the enrollment process?



2017 Therapist Survey: Barriers



2017 Therapist Survey: Barriers

- Caseload size/Time
- Discussing with parents
- Lack of a CP Diagnosis
- Comfort with Enrollment Process
- Proximity to service in Alberta
- Unsure which children on my caseload may have already been registered
- Forms
- Clarity around responsibility for enrollment

2018 Pediatrician Survey

Are you currently diagnosing children with cerebral palsy in your practice?

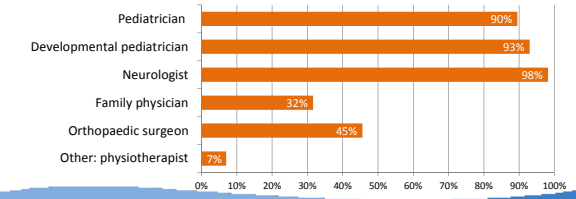
- 45 General Pediatricians
  - 27 (60%) Yes
  - 15 (33%) No
  - 2 (4%) reported 0% of practice is children with CP
  - 1 (2%) did not respond

2018 Pediatrician Survey

	1 (not at all)	2	3	4	5 (very much so)
Providing a diagnosis of cerebral palsy is important.	0%	0%	4%	18%	79%
It is more important to know the cause of a child's motor impairment than to diagnose cerebral palsy.	11%	0.4	33%	14%	2%
I prefer not to label children with a diagnosis of cerebral palsy.	42%	0.4	9%	4%	2%
I don't think it's my role to diagnose children with cerebral palsy.	42%	0.3	14%	12%	7%
Early diagnosis of cerebral palsy is important for families so that diagnosis specific treatments can be provided.	0%	0.1	2%	35%	58%

2018 Pediatrician Survey

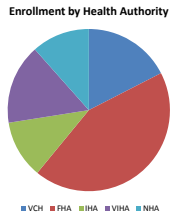
Of the following providers, who do you think can make a definitive diagnosis of cerebral palsy? Please check all that apply.

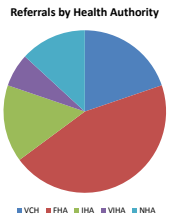


Impact: Referrals

- At enrollment, 65% (559) had seen a pediatric orthopaedic surgeon in the past
- 91 Referrals or re-referrals to Orthopaedics
  - 53 for MP > 30%
  - 35 Clinical exam/question
  - 3 Other

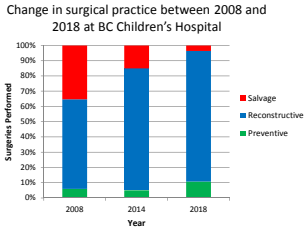
Impact: Referrals





Impact: Surgical Practice

- Number of salvage procedures dropped from 35% to 15% of hip surgeries performed between 2008 and 2014
- In 2018, salvage procedures accounted for less than 4% of interventions performed; all of these were in existing patients or refugees/immigrants new to BC



NEXT STEPS

Lessons Learned

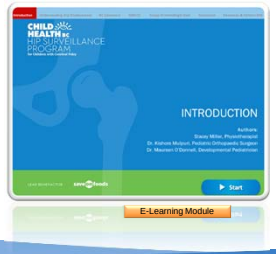
- Physical therapists and pediatricians are supportive of hip surveillance.
- Regional differences in ability to enroll children may necessitate customized strategies.
- Recruitment takes time in the absence of a CP registry.
- Lack of or late diagnosis of CP are barriers to enrollment in hip surveillance.

Knowledge Translation Strategies

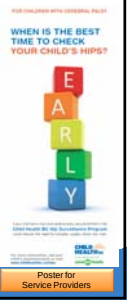
- Targeted education was provided to therapists online and via email, including:
  - Online learning module
  - Clinician & parent education booklets
  - Program website
  - Clinical exam written instructions
  - Webinars
  - In person education sessions
  - Email newsletter updates (biannually)

Knowledge Translation Materials

Parent & Clinician Booklets



E-Learning Module



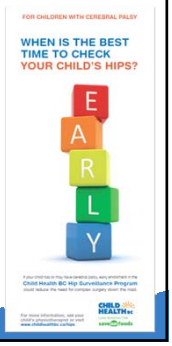
Poster for Service Providers

Current/Planned KT Strategies

- First Nations Health Authority
- BC Pediatric Society
- Doctors of BC
- Pathways
- Regional Peds & GP meetings
- Site Visits
- Infant Development Consultants
- Nursing Support Services
- Pharmacists of BC
- Social Media
- Healthy Start Working Group
- New materials for families

Next Steps

- Regional strategies
  - What would work in your region?
- Profession and parent specific knowledge translation strategies
  - What else can we do to reach pediatricians, family physicians, therapists?



CHILD HEALTH BC HIP SURVEILLANCE PROGRAM for Children with Cerebral Palsy

Thank you

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www.childhealthbc.ca/hips

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