

## **ABSTRACT**

### **AIM**

This study aimed to explore health professional's experiences of implementing hip surveillance for young people with cerebral palsy, and identify any barriers they encounter.

### **METHODS**

A cross-sectional web-based survey of health professionals supporting children with cerebral palsy was conducted. Responses were analysed through mixed-methods. Responses to items presented as ordinal scales were analysed using descriptive statistics and open-ended responses through a qualitative approach to identify themes.

### **RESULTS**

Thirty-two paediatricians, two rehabilitation specialists and 50 physiotherapists completed the survey, with respondents working within both hospital and community-based settings. Barriers most frequently reported were inconsistency in radiology practice and reporting (35%), parent engagement (32%), limited communication between clinicians (31%), lack of clarity in lines of responsibility (27%), and forgetting to undertake surveillance (26%). Four major themes were identified through qualitative analysis: 1) Recognition of the importance of clinical guidelines to hip surveillance, 2) The value of each role in the team around a child, 3) The challenge of sharing responsibility, and 4) The importance of communication in facilitating collaboration.

### **CONCLUSIONS**

Barriers can be encountered at each phase of the hip surveillance process, but there are also factors that act as facilitators. Locally, the results will inform the development of an enhanced, state-wide approach to hip surveillance for all children with CP. The identified barriers do not appear unique to the local context, and the findings may be transferable to other settings. Awareness of the potential barriers and facilitators would be valuable to those implementing hip surveillance in other areas.

### **KEY WORDS:**

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**TEXT:**

Awareness of the importance of monitoring hip displacement in young people with cerebral palsy (CP) has been driven by evidence of the negative consequences of severe hip displacement and dislocation. Severely displaced or dislocated hips can cause pain and significantly impact on quality of life.<sup>1-4</sup> Clinical guidelines for hip surveillance have been developed in many areas.<sup>5-10</sup> These guidelines are informed by evidence from population-based studies that report the prevalence of hip displacement in children with CP to be as high as 35%,<sup>11-13</sup> with a direct correlation between gross motor function, classified by the Gross Motor Function Classification System (GMFCS),<sup>14</sup> and risk of developing hip displacement.<sup>11-13</sup> This knowledge has informed risk-based guidelines, assisting clinicians to determine an appropriate frequency of radiographic surveillance.

Where population-based hip surveillance 'programs' have been implemented, a significant reduction in the incidence of hip dislocation and salvage surgery has been reported.<sup>15-16</sup> Recent evidence also supports the effectiveness of hip surveillance for achieving better hip morphology in young adults with CP, and an associated decrease in hip pain.<sup>7</sup> This long-term follow-up of a birth cohort in Victoria, Australia, highlighted that a significant proportion of children with CP have routine hip surveillance, facilitating timely management of hip displacement. However, some were lost to routine surveillance resulting in poorer outcomes due to later detection of hip displacement and delayed management.<sup>7</sup> Factors contributing to inconsistent implementation of hip surveillance may include lack of clinician knowledge about the need for routine surveillance, differing models of service delivery for children with CP, or limited resources within services.

While clinical guidelines assist clinicians to determine an appropriate frequency of surveillance and facilitate orthopaedic referral, they cannot dictate *how* hip surveillance should be implemented. The development and publication of a clinical guideline without an implementation strategy does not guarantee direct translation of knowledge into a change in practice.<sup>17-18</sup> Identifying barriers to knowledge use is an important component of frameworks for knowledge translation.<sup>19-20</sup> Awareness

of barriers to implementing hip surveillance may help in understanding current limitations and difficulties, and why some children miss on-going surveillance.

To inform development of an enhanced state-wide model for hip surveillance, health professionals were surveyed to explore their experiences. The survey also sought recommendations about key features that, if included in a state-wide model for hip surveillance, would improve current process. The focus of this paper is to report health professionals' awareness and use of national clinical guidelines, and the barriers they encounter when implementing hip surveillance.

## **MATERIALS AND METHODS**

A cross-sectional, web-based survey was conducted through open invitation.

### **Participants**

The target population were paediatricians, paediatric rehabilitation specialists and physiotherapists, in Victoria, Australia working with young people with CP. Invitations to paediatricians were distributed through the Victorian Cerebral Palsy Register, relevant departments of tertiary paediatric hospitals, paediatric departments of other metropolitan and regional hospitals, and to those in private practice. Invitations to physiotherapists were sent to early childhood and special school services, and those registered with a Federal Government initiative funding therapy for children with disability. Physiotherapists and rehabilitation specialists within the state-wide paediatric rehabilitation service were invited through their network. Invitations were followed up by post and e-mail at one and two weeks. Participants gave informed consent for the collection of non-identifiable responses. Ethical approval was granted by The Royal Children's Hospital Human Research Ethics Committee (HREC #34249B).

### **Data Collection**

A web-based survey was conducted using the secure, encrypted Research Electronic Data Capture (REDCap) database.<sup>21</sup> Fifty-three items were presented within 12 sub-sections, with many items conditionally displayed based on prior responses. All responses were voluntarily submitted and non-identifiable, and could be reviewed and amended prior to submission.

Respondents reported their profession, practice setting and experience working with children with CP. They rated awareness and frequency of use of national clinical guidelines for hip surveillance, and identified barriers and facilitators encountered when conducting surveillance. Respondents rated their confidence applying criteria within the guideline; use of the GMFCS and Winters Gage and Hicks (WGH) tools to classify gross motor function or hemiplegic gait patterns, 'stability' of migration percentage (MP), and determining 'pre-puberty' and 'skeletal maturity'. Respondents were asked to describe their experiences with evaluating pelvic X-rays and, if involved, rated their awareness and confidence in measuring MP.<sup>22</sup> All confidence ratings were according to a five-point scale with anchors at 'not confident at all' and 'very confident'. A sixth option allowed respondents to identify if they were 'not familiar with this concept'. Open-ended questions within each subsection allowed respondents to provide greater detail regarding their experiences.

### **Data Analysis**

Survey responses were analysed using descriptive statistics. Associations between awareness of clinical guidelines and years of experience or the proportion of caseload comprised of children with CP were assessed using  $\chi^2$  analysis. A structured qualitative analysis of open-ended responses was also undertaken to derive themes (Table 1). Quantitative analyses were conducted using Stata (version 13.1, StataCorp, College Station, TX, USA). Qualitative data was managed using NVivo (Version 11, QSR International, <http://www.qsrinternational.com>).

## **RESULTS**

Eighty-four health professionals met eligibility and completed the survey. They identified as paediatricians (38%), paediatric rehabilitation specialists (2%) or physiotherapists (60%). They worked across a range of settings and had a range of experience both in years of practice and the proportion of their caseload that is young people with CP (Table II).

### **Awareness and confidence in using clinical guidelines**

Sixty-eight respondents (80%) reported awareness of national hip surveillance guidelines; 46 physiotherapists (92%), both rehabilitation physicians and 29 paediatricians (59%). While there was no association between a respondent's awareness of the guidelines and their years of experience

( $\chi^2=1.86, p=0.87$ ), there was strong evidence of a relationship between awareness and having a larger proportion of caseload comprised of children with CP ( $\chi^2=16.92, p=0.005$ ).

Respondent's confidence in applying criteria within the guidelines is summarised in Table III. Those aware of the guidelines reported moderate to high confidence in using them to determine an appropriate frequency of hip surveillance for an individual child. There was high confidence for classifying gross motor function using the GMFCS. Paediatricians reported lower confidence than physiotherapists in identifying WGH Type IV gait, and were less familiar with the concept. Paediatricians reported comparatively higher confidence in determining when a child would be considered as being 'pre-puberty' or at 'skeletal maturity'. There was wide variation in confidence in assessing 'stability' of hip migration percentage.

### **Barriers to hip surveillance**

Several barriers to using the clinical guidelines were reported, with others related to the overall implementation of hip surveillance (Table IV, Figure 1). Barriers occurred at each phase of the hip surveillance process (Figure 1). Barriers most frequently reported included those related to parent engagement (reported by 32%), lack of communication between clinicians (31%), lack of clarity about who is responsible for surveillance (27%), and forgetting hip surveillance or lack of a reminder system (26%).

One of the larger barriers identified was inconsistent radiology practice and reporting (35% of respondents). Thirty-six individuals (43%) reported directly referring children for pelvic X-rays for hip surveillance. Of these, 13 (36%) stated that they do not routinely receive a written radiology report and 16 (44%) estimated that MP is reported in less than 30% of radiology reports.

### **Experiences when implementing hip surveillance**

Four major themes regarding the implementation of hip surveillance emerged through qualitative analysis. Sub-themes identified within each major theme are summarized in Table V along with representative quotes.

#### ***1. Recognition of the importance of clinical guidelines to hip surveillance***

*“Clear clinical practice guidelines for hip surveillance in children with cerebral palsy according to GMFCS level [facilitate hip surveillance]”* (participant #69, physiotherapist, private practice, 6-10yrs experience).

Participants consistently identified the availability of guidelines, including clear pathways according to GMFCS classification, as a facilitator of hip surveillance (Table V, quotes 1.1 - 1.4). In particular, physiotherapists described that hip surveillance is easier when others working with the child are knowledgeable about surveillance and aware of the guidelines (Table V, quotes 1.5 & 1.6).

## **2. The value of each role in the team around a child**

*“It is everyone's responsibility but ultimately children need one person who knows the buck stops with them, and that should be the primary paediatrician – me”* (participant #68, paediatrician, metropolitan hospital, >20yrs experience)

While respondents identified that each profession has a role in hip surveillance, paediatricians were identified as having a primary role. Clinicians from other professions described their importance to successful hip surveillance, and paediatricians also self-identified as holding primary responsibility (Table V, quotes 2.1 - 2.3). This triangulated with quantitative data, with 91% of paediatricians identifying themselves as being responsible for hip surveillance for children in their care.

Paediatricians described the valuable role physiotherapists play through prompting the need for surveillance (Table V, quotes 2.4 & 2.5). Physiotherapists described their role as multi-faceted; ensuring surveillance is initiated and sustained, providing education to parents, and being well placed to monitor children's physical and functional status (Table V, quotes 2.3 - 2.8).

Respondents highlighted the importance of parent engagement, with parents who have knowledge of the need for hip surveillance being effective facilitators (Table V, quotes 2.9 - 2.12), in contrast to unengaged parents where hip surveillance is more likely to falter (Table V, quotes 2.13 & 2.14). Parent's own competing priorities, limited perception of the importance of surveillance, and poor service coordination were most commonly identified as barriers to engaging parents (Table IV).

## **3. The challenge of sharing responsibility for hip surveillance**

*“My role is important but when the patient sees rehabilitation, orthopaedics and a paediatric service, the boundaries on who should perform hip surveillance get blurred”* (participant #51, rehabilitation specialist, metropolitan hospital, 6-10 yrs experience)

Many respondents reported that hip surveillance can be challenging when it is unclear who is taking primary responsibility (Table V, quotes 3.1 – 3.4). They identified that lack of clarity regarding responsibility can result in children either being overlooked or undergoing X-rays too frequently (Table V, quotes 3.3 & 3.4). They identified that responsibility for undertaking hip surveillance can be shared or transition between clinicians (Table V, quotes 3.5 – 3.8), and this approach was considered advantageous as the many steps involved can be shared among team members (Table V, quotes 3.9 & 3.10).

#### **4. The importance of communication in facilitating collaboration**

*“Collaboration and correspondence from other people involved in the care of the child, especially orthopaedic surgeons/rehab clinics/physios [facilitates surveillance]”* (participant #37, paediatrician, private practice, >20yrs experience)

Several factors relating to communication were deemed important to successful hip surveillance, including communicating with all team members to ensure awareness of the child’s surveillance status (Table V, quotes 4.1 - 4.3). Communication of specific information was considered critical, such as MP from recent X-ray and a plan for future surveillance (Table V, quotes 4.4 - 4.6). In particular, physiotherapists reported that being omitted from correspondence is a barrier to fulfilling their role in hip surveillance (Table V, quotes 4.7 - 4.8).

## **DISCUSSION**

Rather than simply taking an X-ray, hip surveillance is a multi-step process.<sup>1,2</sup> It involves ordering the X-ray, completing imaging, radiologist evaluation, reporting to the referring clinician, interpretation in light of clinical guidelines, developing a plan for on-going surveillance and communication to all involved in the child’s care. Barriers can arise at any phase in this process (Figure 1), resulting in children being ‘lost’ to surveillance and at risk of undetected hip displacement.<sup>7,8</sup>

The perceived barriers to hip surveillance in this study mirror many of those previously reported as relating to adherence to clinical guidelines.<sup>18</sup> Similar to previous reports, lack of awareness of the

national guideline for hip surveillance is a barrier.<sup>18</sup> A significant proportion of paediatricians surveyed were unaware of the clinical guidelines, and clinicians who work less frequently with children with CP are less likely to be aware. Barriers considered 'external' to the clinician were among the most frequently reported, with lack of a reminder system a critical factor. Parent-related factors were reported as a perceived barrier, which is crucial to address given that the survey also identified that parental engagement is *key* to the success of hip surveillance. Factors related to radiology practice and reporting are also an area of significant challenge. The MP is the primary clinical criterion on which frequency of hip surveillance and the trigger for orthopaedic referral are based.<sup>22</sup> Without this essential piece of data available to them, clinicians are unable to interpret and apply clinical guidelines. Consequences for the child can be incomplete hip surveillance leading to late detection of hip displacement, or potential exposure to excessive radiation due to unnecessarily high X-ray frequency.<sup>13</sup>

Interestingly, while identified as common barriers to the use of other clinical practice guidelines,<sup>18</sup> lack of agreement with guidelines and lack of outcome expectancy (that adhering to a guideline will lead to the desired outcome) were *not* identified as barriers to hip surveillance. Those who were aware of guidelines attributed value to hip surveillance, with strong report of clinical guidelines as a key facilitator of hip surveillance.

This study identified several 'hurdles' to hip surveillance that, while not insurmountable, make the process less efficient for both professionals and families. A multi-faceted intervention approach will be required to address these barriers. Foremost, it is crucial that any clinician supporting a child with CP is aware of the prevalence of hip displacement, the consequences of dislocation, the need for hip surveillance and the availability of clinical guidelines. Increasing awareness should be prioritised. Potential strategies to address other barriers may include point-of-care reminders for busy clinicians and for parents caring for children with complex and competing needs, standardised methods and training for those measuring MP, and standardised reporting of hip surveillance results. Continuing professional development will be important, including educational outreach to facilitate change by providing information to clinicians in their practice setting.<sup>23</sup> Further information provision, through print and web-based resources, is important for both clinicians and caregivers to improve engagement in hip surveillance.



This is the first known study to report barriers to the implementation of hip surveillance for children with CP. The inclusion of a qualitative component to data analysis allowed identification of important factors and concepts to aid greater understanding of the experiences of health professionals when implementing hip surveillance, and a deeper understanding of the current challenges.

The survey methodology chosen for this study aimed to explore the experiences of as many health professionals as possible. Despite this intention, there are some limitations. The comprehensive invitation strategy means it is not possible to ascertain how many people the invitation reached and the potential participant denominator is unknown. While health professionals from a variety of practice settings were invited, purposive sampling may have enabled stronger generalisation of the study findings, particularly among rehabilitation specialists with only two responses received from among this group of clinicians. It also is possible that the health professionals who responded to the survey invitation may have had a greater interest in hip surveillance than those who did not respond. This may have resulted in bias in the responses received. The qualitative analysis provided a deeper understanding of respondents' experiences but were likely limited in depth due to the use of a survey to capture responses. Due to the survey methodology, it is also not possible to ascertain if saturation of themes was reached during the qualitative analysis.

Locally, the results of this study will inform the development of an enhanced, state-wide approach to hip surveillance for all children with CP, however the identified barriers are not necessarily unique to the local context. Every child with CP should be monitored for hip displacement, and the steps required in the hip surveillance process are common regardless of geographical location. Awareness of potential barriers is important for anyone working in the area of hip surveillance or managing hip displacement for children with CP. Beyond the publication of a clinical guideline, addressing barriers to implementation throughout Australia will be paramount to ensuring that no child with CP misses hip surveillance, has delayed detection or treatment of hip displacement, and suffers the chronic pain and decreased quality of life associated with *preventable* dislocation.

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**Table 1** Qualitative data analysis process

| Stage of analysis | Data analysis activity  | Number of researchers involved  |
|-------------------|---|---|
| 1                 | Two authors (KW, RT) immersed themselves in the data by reading responses to open-ended survey questions several times. | 2   |
| 2                 | Initial coding of open responses related to health professionals  | Initial coding of barriers to hip surveillance reported in the survey responses was 2 |

- experiences of implementing hip surveillance was conducted by one author (RT) with key concepts mapped against an analysis matrix based on the survey questions
- conducted by one author (KW) against a matrix of categories previously reported as barriers to physician's use of clinical practice guidelines.<sup>18</sup> Additional barriers that were identified as being unique to hip surveillance were added to this matrix as coding progressed.
- 3 A second author (KW) reviewed first-stage coding and discussion was undertaken between the two authors to refine, categorise and group nodes. A second author (RT) reviewed first-stage coding of barriers and discussion was undertaken between the two authors to refine, categorise and group nodes. 2
- 4 Responses to all open-ended survey questions related to both experiences and barrier to implementing hip surveillance were re-read by the two authors (KW, RT) and coded against the refined node matrices 2
- 5-9 An iterative process of thematic grouping of nodes, review and discussion was undertaken until agreement on nodes representing major themes and subthemes was achieved (KW, RT). An audit trail was maintained to document categorising of codes at each stage of review. 2
- 10 Final consensus on 4 major themes was reached through discussion between the 5 authors (KW, RT, JH, HKG, DR). 5

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**Table 2** Characteristics of survey participants

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|                                      | <b>Rehabilitation</b> |                      |                        |                |
|--------------------------------------|-----------------------|----------------------|------------------------|----------------|
|                                      | <b>Specialist</b>     | <b>Paediatrician</b> | <b>Physiotherapist</b> | <b>TOTAL</b>   |
|                                      | n=2                   | n=32                 | n=50                   | n=84           |
| <b>PRACTICE SETTING<sup>†</sup></b>  |                       |                      |                        |                |
| <b>Metropolitan public hospital:</b> | <b>2 (100)</b>        | <b>19 (60)</b>       | <b>10 (20)</b>         | <b>31 (37)</b> |
| <b>Regional hospital:</b>            | <b>1 (50)</b>         | <b>10 (31)</b>       | <b>1 (2)</b>           | <b>12 (14)</b> |
| <i>Public hospital</i>               | 1 (50)                | 8 (88)               | 1 (100)                | 10 (83)        |
| <i>Private hospital</i>              | 0 (0)                 | 2 (12)               | 0 (0)                  | 2 (17)         |
| <b>Community-based:</b>              | <b>1 (50)</b>         | <b>16 (50)</b>       | <b>17 (34)</b>         | <b>34 (40)</b> |
| <i>Public health service</i>         | 0 (0)                 | 2 (12)               | 5 (29)                 | 25 (76)        |
| <i>Private practice</i>              | 1 (50)                | 14 (88)              | 12 (71)                | 8 (24)         |
| <b>Early Childhood Intervention</b>  | <b>0 (0)</b>          | <b>1 (3)</b>         | <b>24 (48)</b>         | <b>25 (30)</b> |
| <b>School service</b>                | <b>0 (0)</b>          | <b>1 (3)</b>         | <b>20 (40)</b>         | <b>21 (25)</b> |
| Years experience working with        |                       |                      |                        |                |
| young people with CP                 |                       |                      |                        |                |
| <1 year                              | 0 (0)                 | 0 (0)                | 1 (2)                  | 1 (1)          |
| 1-5 years                            | 0 (0)                 | 4 (12)               | 9 (18)                 | 13 (16)        |
| 6-10 years                           | 1 (50)                | 8 (25)               | 17 (34)                | 26 (31)        |
| 11-15 years                          | 0 (0)                 | 4 (12)               | 7 (14)                 | 11 (13)        |
| 16-20 years                          | 1 (50)                | 4 (12)               | 6 (12)                 | 11 (13)        |
| >20 years                            | 0 (0)                 | 12 (38)              | 10 (20)                | 22 (26)        |
| % of caseload that is young          |                       |                      |                        |                |
| people with CP                       |                       |                      |                        |                |

|        |         |         |         |         |
|--------|---------|---------|---------|---------|
| <10%   | 0 (0)   | 21 (66) | 7 (14)  | 28 (33) |
| 10-25% | 0 (0)   | 8 (25)  | 9 (18)  | 17 (20) |
| 26-50% | 0 (0)   | 0 (0)   | 8 (16)  | 8 (10)  |
| 51-75% | 2 (100) | 1 (3)   | 14 (28) | 17 (20) |
| 76-90% | 0 (0)   | 2 (6)   | 7 (14)  | 9 (11)  |
| >90%   | 0 (0)   | 0 (0)   | 5 (10)  | 5 (6)   |

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All values are n(%); <sup>†</sup> Participants may work at more than one location/setting; Metro, metropolitan; Rehab, rehabilitation; CP, cerebral palsy



**Table 3** Confidence in determining and applying specific clinical criteria within the national hip surveillance clinical guideline

| Clinical Criteria                                       | I'm not familiar with this concept |       |       | Not confident at all/<br>Somewhat unconfident |         |         | Somewhat confident/<br>Confident |         |         | Very confident |         |         |
|---|------------------------------------|-------|-------|---|---------|---------|----------------------------------|---------|---------|----------------|---------|---------|
|   | Paed/<br>Rehab                     | PT    | Total | Paed/<br>Rehab                                | PT      | Total   | Paed/<br>Rehab                   | PT      | Total   | Paed/<br>Rehab | PT      | Total   |
|   | n=21                               | n=46  | n=67  | n=21  | n=46    | n=67    | n=21                             | n=46    | n=67    | n=21           | n=46    | n=67    |
| Determining an appropriate frequency of HS for a child  | 0 (0)                              | 0 (0) | 0 (0) | 1 (5)   | 2 (4)   | 3 (4)   | 18 (86)                          | 31 (67) | 49 (73) | 2 (10)         | 13 (28) | 15 (22) |
| Classifying a child's gross motor function by the GMFCS | 0 (0)                              | 0 (0) | 0 (0) | 3 (14)  | 1 (2)   | 4 (6)   | 13 (62)                          | 20 (43) | 33 (49) | 5 (24)         | 25 (54) | 30 (45) |
| Identifying WGH Type IV gait pattern                    | 2 (10)                             | 3 (7) | 5 (7) | 8 (38)  | 11 (24) | 19 (28) | 10 (48)                          | 23 (50) | 33 (49) | 1 (5)          | 9 (20)  | 10 (15) |
| Assessing 'stability' of hip MP                         | 0 (0)                              | 2 (4) | 2 (3) | 11 (52)                                       | 18 (39) | 29 (43) | 9 (43)                           | 19 (41) | 28 (42) | 1 (5)          | 7 (15)  | 8 (12)  |

|  |       |       |       |       |         |         |         |         |         |        |         |         |
|--|-------|-------|-------|-------|---------|---------|---------|---------|---------|--------|---------|---------|
| Determining when a child is 'pre-puberty'  | 0 (0) | 1 (2) | 1 (1) | 0 (0) | 19 (41) | 19 (28) | 15 (71) | 22 (48) | 27 (40) | 6 (29) | 4 (9)   | 10 (15) |
| Determining 'skeletal maturity'            | 0 (0) | 2 (4) | 2 (3) | 0 (0) | 24 (52) | 24 (36) | 18 (86) | 17 (37) | 35 (52) | 3 (14) | 3 (7)   | 6 (9)   |
| Determining the point of discharge from HS | 0 (0) | 0 (0) | 0 (0) | 1 (5) | 2 (4)   | 3 (4)   | 18 (86) | 31 (67) | 49 (73) | 2 (10) | 13 (28) | 15 (22) |

All values are n(%); Paed/Rehab, paediatricians and rehabilitation physicians; PT, physiotherapist; GMFCS, Gross Motor Function Classification System, WGH, Winters Gage and Hicks; MP, migration percentage; HS, hip surveillance

**Table 4** Barriers to conducting hip surveillance

| Barriers related to use of clinical guidelines for hip surveillance <sup>#</sup> | n (%)   |
|--|---------|
| <b>Knowledge</b>   |         |
| Lack of <i>[peers]</i> awareness of guideline                                    | 10 (12) |
| Lack of familiarity with guideline   | 3 (4)   |
| <b>Attitudes</b>   |         |
| Lack of agreement with specific guideline, or with guidelines in general         | 0 (0)   |
| Lack of outcome expectancy   | 0 (0)   |
| Lack of self-efficacy  | 6 (7)   |
| <i>Ordering X-rays is not within scope of practice (physiotherapists)</i>        | 9 (11)  |
| Inertia of previous practice   | 0 (0)   |
| <b>External Barriers – guideline related</b>                                     |         |
| Confusing, Cumbersome, Not convenient, Not easy to use                           | 0 (0)   |
| <b>External Barriers – patient related</b>                                       |         |
| <i>[Parent]</i> does not perceive need   | 14 (17) |
| <i>[Parent]</i> resistance/non-adherence, <i>lack of engagement</i>              | 27 (32) |
| <i>Inconsistent attendance at appointments</i>                                   | 6 (7)   |
| <i>Not following through with X-ray/recommendation</i>                           | 11 (13) |
| <i>Parent reticence due to radiation exposure</i>                                | 1 (1)   |
| <i>Parents who speak a language other than English</i>                           | 4 (5)   |
| <i>Parental demands or competing priorities</i>                                  | 5 (6)   |
| <b>External Barriers – related to practice setting</b>                           |         |
| Lack of reminder system <i>[or Forgetting]</i>                                   | 22 (26) |
| Lack of educational materials <i>[and opportunities]</i>                         | 3 (4)   |

|   |                     |
|---|---------------------|
| Cost to patient   | 4 (5)               |
| Lack of insurance coverage  | 0 (0)               |
| Cost to practice/ <i>health service</i>   | 0 (0)               |
| Insufficient staff or consultation support  | 17 (20)             |
| <i>Lack of access to expert opinion</i>   | 5 (6)               |
| <i>Lack of funding for staff/services</i>   | 5 (6)               |
| <i>Working in isolation</i>   | 7 (8)               |
| Lack of time  | 12 (14)             |
| <i>Caseload demands</i>   | 2 (2)               |
| <i>Competing medical priorities for the child</i>                                       | 3 (4)               |
| <i>Time constraints</i>   | 7 (8)               |
| Lack of reimbursement   | 0 (0)               |
| Increased malpractice liability   | 0 (0)               |
| <hr/>   |                     |
| <b>Barriers identified as being specific to the implementation of hip surveillance</b>  | <b><i>n (%)</i></b> |
| <hr/>   |                     |
| <i>Lack of care coordination</i>  | 12 (14)             |
| <i>Inconsistency in clinician providing care</i>  | 5 (6)               |
| <i>Lack of coordination of appointments</i>   | 7 (8)               |
| <i>Lack of clarity about who is responsible for a child's hip surveillance</i>          | 23 (27)             |
| <i>Lack of communication between clinicians involved in a child's care</i>              | 26 (31)             |
| <i>Lack of a method to record and track serial hip surveillance data</i>                | 10 (12)             |
| <i>Radiology-related barriers</i>   | 29 (35)             |
| <i>Inconsistency in MP measurement and reporting by radiologist</i>                     | 9 (11)              |
| <i>Lack of confidence in expertise at local radiology facilities</i>                    | 9 (11)              |
| <i>Lack of awareness /protocols for appropriate positioning of child during imaging</i> | 3 (4)               |

*Delay/lack in receiving Radiologist report*

4 (5)

*Uncertainty regarding referral pathways*

2 (2)

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# Barriers categorised according to the framework by Cabana et al.<sup>18</sup>; Titles in italics were identified in addition to the framework as being specific to hip surveillance. *n*, number of respondents who reported barrier; MP, migration percentage

**Table 5** Summary of major and minor qualitative themes with representative quotes

| Major and minor themes   | Representative quotes†   |
|--|--|
| <b>1. Recognition that clinical guidelines are critical to hip surveillance</b>  |  |
| <ul style="list-style-type: none"> <li>Clinical guidelines are a key facilitator of hip surveillance</li> </ul>                                      | <p>1.1 <i>“Clear clinical practice guidelines for hip surveillance in children with cerebral palsy according GMFCS level [facilitates surveillance]”</i> (#69, PT, private practice, 6-10 yrs)</p> <p>1.2 <i>“Clear guidelines regarding hip surveillance [are a facilitator]”</i> (#32, PT, private practice, 6-10 yrs)</p> <p>1.3 <i>“The standardized protocol for screening recommendations based on GMFCS [is a facilitator]”</i> (#41, paediatrician, regional hospital, 6-10 yrs)</p> <p>1.4 <i>“Having an algorithm/pathway of who/how often needs surveillance [is a facilitator]”</i> (#99, paediatrician, metro public hospital, 1-5 yrs)</p> |
| <ul style="list-style-type: none"> <li>Surveillance is easier when those involved with the child are knowledgeable about hip surveillance</li> </ul> | <p>1.5 <i>“The paediatrician or GP who is aware of the hip protocols and refers as needed [facilitates hip surveillance]”</i> (#103, PT, metro public hospital, 6-10 yrs)</p> <p>1.6 <i>“Lack of awareness of the need for surveillance on the part of the child's paediatrician [is a barrier]”</i></p>   |

(#28, PT, ECS, >20 yrs)

## 2. Hip surveillance relies on a team around the child

- Paediatricians play a primary role
  - 2.1 *“It is everyone's responsibility but ultimately children need one person who knows the buck stops with them, and that should be the primary paediatrician – me”* (#68, paediatrician, metro hospital, >20yrs)
  - 2.2 *“It is up to me to remember to do it and get the family on board and make sure it is done”* (#93, paediatrician, metro hospital, 6-10 yrs)
  - 2.3 *“I believe I am responsible for the WHOLE child and I should ensure hip surveillance happens”* (#19, paediatrician, metro hospital, 11-15 yrs)
- The involvement of a physiotherapist is helpful to others
  - 2.4 *“Prompts from physiotherapists are helpful – they understand the progression and functional significance of hip displacement better than I do”* (#1, paediatrician, metro hospital, >20 yrs)
  - 2.5 *“Physiotherapists working with the child helpfully encourage the parents to follow through”* (#107, paediatrician, private practice, >20 yrs)
- Physiotherapists identify as having a multifaceted role
  - 2.6 *“If the child doesn't have regular surveillance then I feel it is my job to get the ball rolling and get the first*

- Knowledgeable and engaged parents can be effective facilitators of surveillance

*X-ray organised, as well as subsequent ones, if for some reason they slip through the system” (#63, PT, private practice, 6-10 yrs)*

2.7 *“I think it is negligent not to have these discussions with a family in my role as a paediatric physio in the community...we can't ignore this because it has HUGE implications for future function and chronic pain” (#34, PT, ECS, >20 yrs)*

2.8 *“Often physios can see the client the most often and therefore can be in a position to note changes or to ensure follow up is occurring” (#47, PT, CHS, 1-5 yrs)*

2.9 *“Patient/family cooperation and motivation [is a facilitator]” (#57, paediatrician, metro hospital, >20 yrs)*

2.10 *“Parents and families being aware of and understanding hip surveillance, taking an active role in ensuring compliance with guidelines [facilitates hip surveillance]” (#64, PT, metro hospital, 6-10 yrs)*

2.11 *“having proactive parents who feedback on restricted movements, changes in pain, orthopaedic reviews and X-rays [facilitates hip surveillance]” (#87, PT, school service, 1-5 yrs)*

2.12 *“Parental knowledge and recognition of importance of hip surveillance [is a facilitator]” (#49, PT, ECS, 1-5 yrs)*



- Hip surveillance can falter when there are barriers to engaging parents in the process

2.13 *“Family poor understanding, appreciation & stress levels [are barriers] leading to poor compliance for X-ray or review with their paediatrician”* (#101, paediatrician, private practice, >20yrs)

2.14 *“The other problem is those really complex children where the hip surveillance gets 'lost' amongst the other issues going on, either by the doctor or family. I have had a number of instances where I have given the family an X-ray request, they have been overwhelmed and not acted on the request and I forget to remind them and the whole process becomes delayed”* (#11, paediatrician, regional hospital, 6-10 yrs)

### 3. The challenge of sharing responsibility for hip surveillance

- It is difficult to identify who is taking primary responsibility for a child’s hip surveillance

3.1 *“I don't think there is any consensus in the community about who should be responsible. Good developmental and general paediatricians will take on this role but it is not consistent across the state”* (#18, PT, private practice, 16-20 yrs)

3.2 *“My role is important but when the patient sees rehabilitation, orthopaedics and a paediatric service, the boundaries on who should perform hip surveillance gets blurred”* (#51, rehab specialist, metro hospital, 6-10 yrs)

3.3 *“Some kids have too many people wanting to do hip surveillance and others can’t get anyone consistently*

- Responsibility can be shared or transition within the team around the child
  - 3.4 “Because this is not always clear children do fall through the cracks” (#102, paediatrician, regional hospital, >20 yrs)
  - 3.5 *“I feel that each practitioner involved in the care of the patient with cerebral palsy has a responsibility to ensure that hip surveillance is occurring and being effective, rather than the responsibility being with one single practitioner”* (#69, PT, private practice, 6-10 yrs)
  - 3.6 *“I think ultimately it is a joint responsibility between all who is in contact with the client”* (#47, PT, CHS, 1-5 yrs)
  - 3.7 *“If there is already an orthopaedic specialist involved I assume they will manage this unless specifically documented in correspondence that I am to continue”* (#11, paediatrician, regional hospital, 6-10 yrs)
  - 3.8 *“There are some patients I am the key doctor so will do hip surveillance, others might access orthopaedics so they will then do it, others are with community paediatrician so they will do it”* (#76, rehab specialist, metro hospital, 16-20 yrs)
- A team approach is advantageous
  - 3.9 *“The paediatrician would usually ensure that the client has regular hip x-rays and reviews. It is also the*

*to do it”* (#76, rehab specialist, metro hospital, 16-20 yrs)

*parent's responsibility to ensure these appointments are attended. The school physio often follows up on the parent to make sure this has happened. Maintaining hip surveillance is a joint effort between all involved in the child's care" (#87, PT, school service, 1-5 yrs)*

3.10 *"[Hip surveillance should be] a coordinated team effort, both hospital and community-based" (#55, PT, ECS, 11-15 yrs)*

#### 4. The importance of communication in facilitating collaboration

- Communication between all clinicians in the team around the child is important

4.1 *"Collaboration and correspondence from other people involved in the care of the child, especially orthopaedic surgeons/ neuromuscular clinics/ gait labs/ rehab clinics/ physio's etc." (#37, paediatrician, private practice, >20yrs)*

4.2 *"Good communication between the family, GP, [tertiary children's hospital], [rehabilitation service] and the paediatrician [is a facilitator]" (#102, paediatrician, regional hospital, >20 yrs)*

4.3 *"Clear communication from hospital to parents and therapists re: plan for hip surveillance" (#49, PT, ECS, 1-5 yrs)*

- Specific information is needed to support hip surveillance

4.4 *"Radiology not calculating migration percentage, or not reporting it correctly [is a barrier]" (#51, Rehab*

planning

specialist, metro hospital, 6-10 yrs)

- 4.5 *“Clear documentation and correspondence from the medical teams involved in the child's care, outlining who is taking responsibility for monitoring the child's hip status and when the next x-rays are due”* (#104, PT, private practice, 11-15 yrs)
- 4.6 *“correspondence from paediatrician or orthopaedic surgeon regarding date and result of hip X-rays, including important specific information such as 1) hip migration percentage and not just a comment that the hips are OK, 2) time for the next hip X-ray”* (#83, PT, school service, >20 yrs)
- Community physiotherapist cannot effectively play their role when out of the communication loop
- 4.7 *“in the community I often don't get any feedback specific to hip surveillance from clinicians, only what parents are able to report”* (#92, PT, ECS, 11-15 yrs)
- 4.8 *“Not getting feedback from specialist appointments, especially in the school setting, not knowing what the recommendations and management may be therefore not being able to follow up in the school setting or remind and support parents”* (#47, PT, CHS, 1-5 yrs)

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†Each participant is identified by their unique survey ID, specialty, work setting and years of experience category. GMFCS, Gross Motor Function Classification System; PT, physiotherapist; yrs, years; metro, metropolitan; ECS, early childhood service; CHS, community health service; rehab, rehabilitation; GP, general practitioner; MI, migration index



**Figure 1. Legend:** The process of hip surveillance can be considered as occurring in a continuum comprised of five major phases. Three main barriers were identified as spanning the whole process, potentially creating a barrier at each phase. Barriers were also identified as occurring within each phase of the hip surveillance process.



# Health professional's experiences and barriers encountered when implementing hip surveillance for children with cerebral palsy

**Type of Manuscript:** Original article

Kate L Willoughby<sup>1,2</sup> Consultant Physiotherapist, Postgraduate Research Fellow  
Rachel Toovey<sup>1</sup> Physiotherapist, Research Assistant  
Jan M Hodgson<sup>3,4</sup> Research Fellow, Senior Lecturer  
H. Kerr Graham<sup>1,2,4</sup> Consultant Orthopaedic Surgeon, Professor of Orthopaedic Surgery  
Dinah S Reddihough<sup>1,4,5</sup> Consultant Paediatrician

<sup>1</sup>Centre of Research Excellence in Cerebral Palsy, Murdoch Children's Research Institute, Flemington Road, Parkville, Victoria, Australia

<sup>2</sup>Orthopaedic Department, The Royal Children's Hospital, 50 Flemington Road, Parkville, Victoria, Australia

<sup>3</sup>Murdoch Children's Research Institute, Parkville, Victoria, Flemington Road, Parkville, Victoria, Australia

<sup>4</sup>Department of Paediatrics, The University of Melbourne, Carlton, Victoria, Australia

<sup>5</sup>Neurodevelopment and Disability, The Royal Children's Hospital, 50 Flemington Road, Parkville, Victoria, Australia

## **Corresponding Author:**

Kate Willoughby  
Orthopaedic Department  
The Royal Children's Hospital  
50 Flemington Road  
Parkville, Victoria, Australia, 3052  
Telephone: +61 3 9345 4038  
E-mail: kate.willoughby@rch.org.au

## **WHAT IS ALREADY KNOWN ABOUT THIS TOPIC**

1. Hip displacement is common in children with cerebral palsy
2. When undetected or left untreated, hip displacement can progress to painful hip dislocation and a significant impact on quality of life.



3. Hip surveillance programs successfully reduce the incidence of hip dislocation by active screening and detection of hip displacement

#### **WHAT THIS PAPER ADDS**

1. Health professionals recognise the importance of hip surveillance, but some remain unaware of the existence of clinical guidelines
2. There are several barriers to implementing hip surveillance that span the continuum of the surveillance process
3. Hip surveillance can be supported through utilising the skills of each person in the team around the child, by sharing responsibility and through good communication.

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**Author/s:**

Willoughby, KL; Toovey, R; Hodgson, JM; Graham, HK; Reddihough, DS

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