

Falls and Walking Balance in Young People with Cerebral Palsy: A Report on Patient and Public Involvement and Engagement

NIHR Research and Design Service for Yorkshire and Humber PPIE Call 8

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1. Introduction:

Cerebral palsy is a condition that results from injury to the developing brain during pregnancy, birth or in early childhood. It is one of the most common causes of childhood disability in the UK. Cerebral palsy (CP) causes problems with movement and posture that may change the way a person walks, and how easily. Although the initial brain injury does not change, the effect on movement and the ability to walk does change because of how bones and muscles grow. As such, people with cerebral palsy often find it harder to walk during or after adolescence. It is thought that walking balance (sometimes called dynamic stability) may play a significant role in this change. These difficulties may also increase the risk of falls.

40-70% of adults with cerebral palsy experience falls, which have been shown to negatively affect quality of life, self-confidence, and participation in daily activities, as well as increasing the risk of injury and death. The number of falls in children and adolescents may be similar, with one study finding that young people associated poor balance and stability with fear. This fear led them to perceive some routine activities as dangerous and act as a barrier to activity participation. However, further research is needed to explain the relationship between walking balance and the risk of falling and their influence on the health and daily lives of young people with cerebral palsy. Indeed, studies into methods to reduce falls and prevent worsening physical abilities after adolescence have been highlighted as a priority by the cerebral palsy community.

There are many ways a health professional may assess the ability of a person to maintain their balance when they visit clinic, however these have not been proven to predict walking balance or fall risk. They are also based on subjective judgements made by the clinician, which may limit their accuracy. However, motion capture technology - which describes ways of digitally recording and measuring human movement (often the same as that used for special effects in film) - may provide more walking-specific detail and insight. Indeed, some of these measures use the same information collected as part of three-dimensional gait analysis,

a service provided at the Sheffield Children's Hospital that assesses how people walk. Gait analysis is recommended for individuals with cerebral palsy in order to measure function, inform clinical decision making processes, and improve outcomes. However, there has been no published attempt to relate objectively measured walking dynamic stability (hereby referred to as 'walking balance') to falls risk, nor validate these measures against current clinical standards in young people with cerebral palsy. As such, there is a clinical imperative to explore the relationship between falls risk and walking balance, and understand its impact on the lived experiences of young people with CP.

This research proposal, therefore, asks: Is falls risk associated with impaired walking balance in young people with cerebral palsy, and how does it relate to their experience of daily walking?

2. Aim:

- Confirm whether walking balance, falls or fall avoidance are research priorities for the group.
- Determine what falls, 'dynamic stability' and 'balance' mean to the young people and agree on the term(s) to use in future discussions and proposals.
- Gain insight into the experience of falls, fall avoidance, and walking balance for the young people with cerebral palsy, including how these experiences have changed with age.
- Gain insight into the acceptability and utility of gait analysis and wearable technology for the young people with cerebral palsy.
- Gain initial user feedback on a questionnaire designed to identify fall risk.

3. Recruitment:

Individuals were eligible to contribute if they had a clinical diagnosis of CP, aged between twelve and eighteen, and regularly walked independently without walking aids. For practical reasons as well as budgetary constraints, those with severe learning difficulties or who were unable to participate in group discussions without an interpreter were not eligible to contribute (but should be considered in future PPIE proposals). Six contributors were sought, a number regarded as acceptable for focus group-type activities and the maximum number that could be funded with the available budget.

Contributors were sought from multiple sources and wide geographical areas to maximise the probability that the group would be representative of the population of interest (young people with CP in the UK). In line with data protection laws and guidance, first contact with young people and their families was made by the clinician known to the family, who would then gain consent to share their contact details with the PPIE project lead (author). Services at the Sheffield Children's Hospital (SCH) included orthopaedic clinics specialising in CP, the mainstream community physiotherapy department, extended scope practitioner clinics

specialising in CP, and the gait analysis service. A single-sided information sheet for clinicians, families and young people was produced that provided a summary of the project and contact details (Appendix 1).

A charity - CP Teens - were also contacted and asked to promote the opportunity with their members. Although the charity were unable to help directly due to the volume of such requests they receive each month, one of their ambassadors did agree to endorse the project. They are an active blogger with links to organisations and individuals pertinent to the project and kindly agreed to support the project by sharing a post on Twitter containing the information sheet and encouraging people to apply. The interest this generated on Twitter provided access to often hard-to-reach groups and individuals typically outside the reach of local services.

All the recruiters were encouraging and positive about the project, and agreed to sign-post eligible families and young people. Although some agreed to look retrospectively at their caseloads, the favoured approach was generally 'as-they-attend'. In part, this was due to the busy caseloads clinicians were managing, with some displaying reluctance to make contact with families due to both time constraints and the (possibly unfounded) fear that these families might then seek an earlier follow-up or re-referral than would be otherwise indicated.

However, after two-weeks without recruiting from the above sources, opportunities to conduct the PPIE activity within the holiday period were shrinking. A decision was made, therefore, that the project lead (author) would actively recruit from families known within the service. Therefore, all six of the contributors were people identified as previous gait analysis service users. Approximately fifteen eligible young people were identified from the records in the past year and contacted by phone. This proved to be a fast and effective way to recruit individuals, giving an opportunity for young people and their families to ask questions or seek clarification. These calls became more refined as it became clear that a proactive approach would be required to ensure people would engage. For example, explicitly gaining consent to be called for a decision rather than simply leaving instructions on how to reply if they decided to contribute. In this way, enough participants were recruited within a week.

4. Contributors:

Six young people contributed to the PPIE. They were aged between thirteen and seventeen (mean and standard deviation, 16 ± 2 years). Three were male, three female. Two were functionally categorised by the Gross Motor Functional Classification Scale (GMFCS) as level I and five as level II (on a five point scale where a higher number indicates a more severe presentation). Two had hemiplegia (involvement on one side of the body), five had diplegia

(involvement primarily of both lower limbs). They were from a relatively wide geographical area, including West and South Yorkshire, Derbyshire, and Greater Manchester.

One of the contributors did not feel confident enough to participate in the group workshops, and therefore agreed to a separate interview, which was conducted in the presence of their parent (who also contributed to the conversation). The remaining five contributed to the online workshops on both occasions.

5. Description of the PPIE Activity:

Once the group had been identified, it was possible to confirm two dates on which to hold virtual workshops. These workshops would be two-to-three hours each using the online video conferencing platform Google Meet. Prior to the event, those involved were kept up-to-date by email, informing them of dates, times, access instructions, and expectations. This was followed-up with a pack that included printed information sheets, consent documents, activity instructions, snacks, pen and paper (for use during the events for note taking etc.), and materials for the first activity (playdough and spaghetti). The packs were posted to every family a week before the event.

Written consent is not required for PPIE activity but because of the involvement of young people (including those under the age of legal consent), the lack of local guidelines, and the potential for use of social media, a decision was made to garner consent through the use of bespoke consent document (Appendix 2). This would document the consent/assent of the contributor and the parent/guardian (for contributors under sixteen).

Three additional facilitators joined both workshops. Two of these individuals were employees at the Sheffield Children's Hospital, with one representing the research and innovation department (providing administrative and technical support) and the other a knowledgeable clinician with previous PPIE experience, who was able to co-facilitate the discussion where necessary, as well as provide feedback on the performance of the project lead. The third facilitator was a member of the public, an adult with a diagnosis of CP known to the project lead. They talked to the group about their own experiences of walking, falling, and how their balance had changed with age. It was hoped that this talk would compliment the background introduction and provide an example of the impact on an individual's lived experience. To ensure facilitators were adequately prepared and able to map the group discussions to the aims of the project, a programme for the two days was shared and a work-board of topics and key questions created that would help stimulate discussion within the group (Appendix 3). All facilitators were contacted in the week leading up to the workshops to discuss their input and subsequently met as a group shortly before the first workshop to ensure that the platform was running smoothly and any technical issues resolved.

Contributors would access the event from their own homes and were encouraged to use their cameras in order to increase a sense of connection with the group and check how actively individuals were participating or listening. They were also encouraged to have an adult they trusted available (but not actively on the call) should they require any support during the event. They were also provided by a mobile number of one of the team to contact if there were any issues (for example, internet drop-outs).

All contributors were able to access Google Meet with the link provided without any further support. The first workshop began with introductions and an outline of the workshop ground-rules, schedule, and aims. A short presentation on the background of the proposal followed, including why the topic was important to clinicians, what is known about the topic so far, what the research might add to our understanding, and how it could be clinically beneficial. Informal interactive elements to this presentation were included (e.g. guessing how much of the time spent walking is on one leg) to encourage active participation early on. A further presentation lead by the member of the public on their own experiences followed before the conversation opened up to the group more formally, details of which are documented below.

Two supplemental activities were planned for the workshops. The first required contributors to photograph or film locations or obstacles that they found challenging prior to the workshop, which would be shared with the group as a way to explore environmental factors that impeded mobility, and the effect these had on the lives of the young person/people. The second activity was designed as an ice-breaker at the start of the group discussions in the first workshop. It was also intended to explore the different interpretations of stability and balance, providing a spring-board for conversations focussed on the definition of dynamic stability and balance as it relates to human mobility, and what terms should be used by the group going forward. This activity involved creating a structure built of spaghetti and playdough. Half of the contributors were asked to build the 'tallest and most well balanced' structure possible, the other half asked to build the 'tallest and most stable' structure possible. Comparisons between the different structures made, and the thought processes behind them were shared before the conversation developed further.

Two weeks would elapse between the workshops, which provided an opportunity to reflect on the content of the first and plan for follow-up on questions or topic-areas that were under-explored or required clarification.

The topics covered in the first workshop included: understanding and exploring what dynamic stability and balance meant to the young people, whether they perceived balance as a limiting factor in their own walking, whether they experienced regular falls or fear of falling,

and how this had changed from being younger children. The second workshop began with a summary of the first before moving on to discussing goal setting (has balance been discussed with a clinician? Was improving your balance ever an aim of intervention?), their experiences of using the gait lab service and the information this generates, whether they felt a measure of walking balance would be of potential benefit to them, and whether they utilised devices to monitor activity or health more generally (e.g. pedometers, heart rate monitors).

Both workshops and the one-on-one interview were recorded and have been saved on a secure server at the Sheffield Children's Hospital.

6. Discussion:

The following discussion is based on the recorded workshops and interview. Reflections have also been discussed between the facilitators to explore key points and check for alternative interpretations. All contributions have been anonymised and some discussions may be paraphrased. Direct quotes have also been included where required.

6.1. Defining Dynamic Stability and Balance:

“[Balance means] standing on your own two feet”

Anonymous contributor

The activity in which contributors are asked to build the tallest structure from the playdough and spaghetti was well received, with laughter helping to break the tension and create a palpable sense of growing ease. One person could not participate, as an unplanned hospital admission that day meant they could not access their materials. Another mislaid theirs, and improvised with shelving planks instead (against advice!). The task was useful as an informal opportunity to begin talking with each other and become accustomed to the virtual format before discussions took a more consequential turn. It also led to a conversation about how balance and dynamic stability were interpreted by the group.

On the whole, it seemed that the group were comfortable with using the term 'balance' and had an intuitive understanding of its meaning that would be consonant with clinical definitions (broadly, the ability of an individual to maintain or return to a state of equilibrium, remain upright and prevent a fall). Interestingly, several group members started to link balance with other characteristics, such as 'consistency' and 'stability', where consistency referred to the ability to maintain gait speed irrespective of the environment (such as uneven ground) and stability was the state achieved through balance (i.e. remaining upright). This former observation led to a question regarding the repercussions of 'walking

with impaired balance' without necessarily prejudicing the conversation to only focus on fall avoidance; in other words, how does poor balance effect walking ability? The responses included "walking more slowly", a perception of general increased difficulty, increased risk of tripping, and increased risk of falling. These responses confirmed the idea that walking balance (or dynamic stability) is perceived to be closely aligned with walking performance more generally, that slower speeds are perceived as mechanism to maintain balance or stability, and that a failure in this endeavour is principally linked to falling.

On the definition of 'dynamic stability' the group were less forthcoming, with the exception of the observation that "balance is what makes you stable". When asked directly, most agreed that they did not have an intuitive understanding of what this term meant. This will be important to consider when designing lay summaries and questionnaires in the future in order to avoid confusing language or misinterpretation. No consensus was made on the use of 'walking balance' as an alternative as the conversation faltered and required a change of direction to maintain momentum. However, based on the discussion about 'balance' (above), there appears to be sufficient alignment of concepts between contributors and clinical definitions to be used as an acceptable alternative.

6.2 Personal Experiences of Balance and Falling:

All six of the contributors had personal experiences of falling, or making adjustments to avoid falling by changing how they walked and the activities in which they participated.

"My balance isn't the best...because of surgery, there are repercussions if I fall"

Anonymous Contributor

For two of the six, there was an increased sense of "vulnerability" associated with having impaired walking balance. Another talked about feeling very anxious when in challenging or public environments. For one, this was because of a perception of being at higher risk of injury should they fall due to their previous surgery. Whether caution has been advised long-term by their surgeon or not is unclear, however, it is important to note the strong psychological and emotional links that are being drawn by these contributors, highlighting the need to address the psychosocial impact of balance and falls for young people with CP.

A further contributor added that, for them, it was not just about feeling vulnerable but appearing to be vulnerable to others. Several people agreed that they disliked the idea of others noticing if they had difficulty with walking, with one expressing frustration at the occurrences in which they felt that other people had made an assumptions about how stable

they were: “I can look unstable to others but that doesn’t mean I’m going to fall...it’s just how I walk”. Indeed, there was a general consensus that one of the worst aspects of having a fall was the unwanted attention from others, particularly strangers, even if it was well-meaning. These falls were talked about as being “humiliating” and “embarrassing”. For some, this was worse as a teenager, as it was seen as ‘normal’ for young children to fall over but less usual for older children and adolescents. For others, they talked about being more used to falls, of being more accepting of their ‘limitations’, indicating that they had developed a type of resilience (“I was used to it by then”). One contributor added that although they were very self-conscious in public, they were far less so in their school setting because they felt that ‘everyone knew me or knew about me’. In other words, their disability was more common knowledge and thus paid less attention to, which made them feel more comfortable in this environment. Another factor to consider in future research, therefore, is the relationship of the impairment (and the individual) to the environment.

Several of the contributors acknowledged that there were activities they avoided because of a perception of risk: “I want to be able to do stuff that other people can do, but I can’t”. The examples given typically related to sporting activities and in one instance to family walks. Several factors limited their participation, including: fear of injury and pain; enjoyment of activities; fatigue; and other people’s perception of risk. Walking balance was directly attributed to the (in)ability to enjoy certain activities because of the additional concentration required to remain mindful of the environment and certain obstacles (e.g., uneven ground). This was further related to fatigue and an inability to appreciate other aspects of their environment (such as ‘the view’ or wildlife). Additionally, two contributors talked about having to sit-out of P.E. because their teachers perceived it as too high risk: “I was never allowed to do P.E. because of my disability, because of my balance...I wanted to but they never allowed me”. And: “I don’t want to sit out but I have to because of my safety...the teachers said that [P.E.] would hurt me”. The alternative provision in one instance was further Math homework. These experiences further highlight the multi-dimensional impact of impaired walking balance and the profound affect that it can have on participation in everyday activities, including sport, which is universally recognised as a crucial factor in maintaining health and wellbeing, especially for those with CP. It will also be important to consider the relationship of walking balance with energetics, fatigue, and dual tasking.

A further factor identified by the group was the requirement to make practical adjustments to their everyday lives, for example planning ahead to ensure they always have someone with them in case of a fall (as they struggled to get off the floor again), leaving classes early to avoid busy corridors, and taking stairs more slowly, more cautiously. These were generally seen as reasonable adjustments and not identified as a priority for change by the individuals, but it is useful to reflect on the wider impact of walking balance and the mitigation strategies employed by some.

A summary of the extrinsic (environmental) and intrinsic (individual) factors linked to walking balance by the contributors can be found in Table 1.

Extrinsic Factors	Intrinsic Factors
Open spaces	Self-awareness and risk assessment
Crowds	Self-confidence
Uneven ground	Anxiety and fear
Wet or icy (slippery) ground	Concentration
Doorways and thresholds	Fatigue
Steps and stairs	Eye-sight
Tight spaces (indoors)	Pain
Unfamiliar environments	Resilience
Expectations of others	Ability to fall 'safely'
Availability of resting places or supportive furniture	Strength
Task requirements (e.g. carrying objects)	Balance
Walking aids	Walking function
	Motivation (ability to enjoy a task)

6.3 How Balance and Falls Have Changed With Age:

All six of the contributors reported falling less often with age. There appeared to be a general consensus that this change was related to an increasing self-awareness of their own physical limitations and the ability to identify, assess and avoid risk (such as avoiding cobblestones on the street). For some, this self-awareness was linked to a more general change in their understanding of CP. Several contributors also explained the change with reference to the ability to 'save themselves' and fall safely, or to fall in such a way as to avoid injury. Some also talked of feeling better equipped or less upset by the fall itself ("I'm used to it"). This indicated that not only were falls less frequent but had also become less consequential (from the perspective of pain or injury). However, it is possible that activity participation and further psychosocial sequelae associated with fall avoidance and impaired walking balance may grow in significance despite fall frequency improving, as discussed above. This additional complexity would need to be addressed by any future research. It may also be pertinent to ensure that the research targets a wider age range than originally assumed, including not only young people and adolescents but younger children also.

6.4 Utilisation of Three-Dimensional Gait Analysis and Wearable Technology in Daily Life:

The objective of this topic was to explore how walking balance outcome measures might be accessed, interpreted and used by young people with CP and complement the gait analysis data already available. However, the discussion highlighted a number of important factors that had not been anticipated and pre-empt these questions. First, however, it is necessary to understand something of the gait analysis service appointment and result feedback processes.

Gait analysis appointments are approximately two hours long and typically involve bi-planar video and three-dimensional motion capture data collection, followed by a clinical examination. These data require processing before they can be further analysed and written into a report, which can take up to half a day more. These reports are reviewed at a bi-monthly clinic with the multi-disciplinary team, after which any recommendations and clinical decisions are documented and shared with the referring clinician. As such, patients and their families do not receive any initial feedback during the appointment itself. Instead, they are advised that their results will be discussed with them at the next appointment with their referring clinician (typically an orthopaedic surgeon).

It was surprising, therefore, to discover that only one of the six young people involved in the workshop reported having explicitly talked about the results of their gait analysis with their clinician. Four young people did not recall discussing their findings with the referring clinician, one recalled that the results were briefly summarised as “worse”. These young people were known to different clinicians, indicating that this experience may not be explained by a single individual. In addition, the one young person that did discuss their results in any detail did not feel like they could understand the results and essentially deferred their decision-making regarding surgery to the consultant in question, although they reported having greater confidence in their decisions because of the use of gait analysis data.

“I just go along with what you say because...you know what works and I just go along with it and agree because I don't know or understand it”

Anonymous contributor

Despite this, many of the young people interpreted their opportunity to see the 3D model (created on our systems for the purposes of later generating the clinical data used for the analysis) as their feedback from the session, purporting to be able to ‘see’ the important features and reporting satisfaction in this process. This is not how the model is presented during the clinical session, as it does not represent any meaningfully interpretable data,

although it is generally of interest to the patient due the novelty of seeing oneself recorded in this way.

When asked about whether they would prefer to have better access to the gait analysis results, there was not an immediate up-take from the group. However, it is not clear whether this is because they perceive gait analysis results as difficult to interpret, as being irrelevant to their own goals, or due to uncertainty about the content of these results. The discussion, therefore, turned to how individuals had evaluated the success of previous surgery, which is a key application of gait analysis for orthopaedic surgeons. Several of the contributors talked openly about previous orthopaedic surgery, including de-rotation osteotomies, which are notoriously difficult to judge objectively if relying on visual assessments alone. The general consensus from these individuals was that they relied on functional outcomes, such as being able to run and participate in football or complete a kick in martial arts with both legs, or simply on how walking “felt”. There was a perception that gait analysis was more useful for clinicians because “they’re not in my body”. When asked whether balance had been a specific target of any intervention (physiotherapy, orthotics, or orthopaedic surgery), four of the group couldn’t recall explicitly targeting their balance or identify improving balance as a goal with their clinicians. Indeed, goal-setting in general was not identified as routine practice by the contributors. One individual reported having the expectation of improving fall frequency with their surgery, which they judged simply on the number of falls they experienced post operatively. Another contributor recalled trying to improve their balance through physiotherapy programmes when they were younger, the success of which was measured by the type of walking aid they were able to use (i.e. less restrictive types). These reports, therefore, beg the question: how important is it to young people to access objective information about their health, activity, and health? And how does this relate to their emerging sense of autonomy and the expectation that they should be increasingly responsible for - and involved in - their health decision making processes?

More hopefully, four of the group reported having used some form of wearable device or biometric data in the past, such as number of steps or heart rate. When asked, accessing the technology - whether through mobile phones or other wearable products - was not identified as a limitation to using such data, and most agreed that when it was used it was useful as a way to stay motivated when, for example, attempting to maintain a baseline of physical activity. This is important to note, since physiotherapy exercise and stretching programmes were universally described as “boring” and “repetitive”. Most agreed that having a more sensitive measure relevant to the exercises they were doing might help with compliance.

7. Summary:

In summary, impaired walking balance was experienced by every member of the PPIE group and closely related with walking ability. The principal concern was one of falls and fall

avoidance, although some comments also related to the appearance of gait, self-image and self-confidence. Falls and impaired walking balance appears to have a direct impact on the motivation and ability of these individuals to participate in everyday activities and access or enjoy some environments, particularly outdoors. There is a suggestion that psychosocial factors, such as anxiety or feeling self-conscious, are also associated with walking balance. This group discussion, therefore, confirms walking balance and falls as a research priority for young people with CP. In addition, this research will have to consider the effect of walking balance and falls across a wider age range than initially assumed given that fall frequency and risk of injury was considered to be greater in early childhood. Although it remains important to note a trend towards self-awareness and risk avoidance and thus reduced participation in later childhood and adolescence.

The term 'dynamic stability' was not familiar or easily interpreted by the group, although there appeared to be an intuitive understanding of 'walking balance', the term used without issue throughout the group discussions, suggesting that this is a more acceptable term to use in future research proposal, particularly in plain English summaries.

The group's experiences of accessing result from their own gait analysis was more mixed. Contrary to expectations, only one of the group could recall having discussed these results with their consultant clinician to any significant degree. What's more, these results were not seen as easily comprehensible and therefore did not inform the individual's own decision making, beyond having greater confidence in the advice of their clinician. This raised questions of autonomy and informed decision making, which are evolving but critical concepts during adolescence that may be closely related to compliance and positive health choices, the ethical issues notwithstanding. In addition, for some individual's within the group gait analysis data was not perceived as critical to the task of understanding their own walking ability, including their response to surgery. Rather, they appeared satisfied rely on 'feel' or functional targets, such as walking with sticks instead of a frame. A separate service improvement project has been initiated to explore how representative these experiences are of gait analysis service users, including addressing how results are currently accessed and used by children, young people, and their families.

Future research into walking balance and falls in children and young people with CP should consider: how these concepts change with age; how they relate to walking function (including kinematics and compensatory strategies); how waking balance behaves relative to energetics and fatigue; dual-tasking; environmental factors (e.g., not solely applied in the laboratory environment); the impact on participation and psychosocial wellbeing; and how the information should be presented to service users and clinicians alike.

8. Reflections:

8.1 What Went Well:

In general, this PPIE project went smoothly and broadly as planned. All six contributors were recruited within a short time-frame once a more proactive approach was adopted. The discussion and interview had 100% attendance on every occasion, which suggests that online platforms may provide a more convenient method for young people to engage in PPIE. In fact, one member was able to contribute from their hospital bed following an unforeseen admission. Therefore, online workshops may provide an opportunity for individuals to access and contribute to PPIE that would otherwise find it difficult to engage because of difficulty travelling or accessing certain environments. Improving inclusivity is an important consideration for PPIE and although there may be technical barriers to using online platforms, there are clearly some benefits in terms of accessibility.

Due to the convenience of the online format, it was also possible to conduct the workshops over several days without the burden of travel, giving an opportunity to reflect on the course of the conversation and seek clarity or explore related topics.

8.2 Challenges:

As discussed, it was not possible to recruit from sources outside of the families I could access directly through my own service. This will be important to consider when designing recruitment strategies for the research itself, including consideration of the barriers for practitioners when recruiting in clinic and the importance of engaging them in the objectives of the research project.

Despite the convenience of the online format, there were some challenges. First, it was difficult to complete the requisite documents prior to and following the workshops. I had to chase people on the phone several times to ensure that consent documents were received prior to the event. Technical competence may be one of the limiting factors (documents had to be signed digitally), however it has been difficult in general to ensure contributors responded to requests remotely, even when sending forms out in the post with stamped and addressed return envelopes. To date, I have had only one questionnaire returned and no feedback from the contributors, with the exception of one email from a parent who said: “[she] really really enjoying it, she’s talked about it so much!”. Further phone-calls will be made in the coming weeks once enough time has elapsed to give individuals reasonable time to respond to the latest communication. Providing the vouchers to individuals remotely was also more complicated and time-consuming. Had people attended face-to-face sessions, I believe many of these practical issues would have been easier and response rates far better.

The other challenge related to the virtual nature of the workshops relates to the task of fostering a group dynamic and dialogue. The contributors talked very little amongst themselves and were reluctant to speak-up at all unless asked questions directly. To some extent, this may be one of the general challenges of attempting to engage young people in group discussions but I believe it was made harder by the remote nature of the conversations. The discussions, therefore, relied heavily on me being able to essentially conduct a series of semi-structured interviews within the group and whilst there was a lot of important information propagated and shared, it is possible that we missed something more novel and relevant without the group interactions.

Having an experienced PPIE facilitator available was useful as a way to reflect on my own performance. I found the challenge of facilitating these conversations, listening to the answers and responding sensitively, following-up on themes with other members, and keeping track of the session objectives and topic development whilst maintaining momentum a difficult task. Although the activity acted as a good ice-breaker, my first mistake was to pitch my discussion about the definition of terms at a level that even undergraduates may have struggled with, and imply that there was a 'right' answer by getting excited about some responses, rather than framing the conversation to concern only what the terms mean to them (rather than what they 'understand' of the terms, which may be intimidating and prejudice responses). This section felt stilted and broke the momentum and pace generated within the activity. This was recovered during further topics with some gentle guidance of my co-facilitator.

Finally, the method by which the young people remain engaged in the ongoing PPIE (keeping up-to-date with the proposal development and helping with the plain English summary) is unresolved. There was no agreement as to what direct format would be acceptable to the group. Everyone - parents included - preferred for the main communication to be through email with their respective parents. They felt that they were far less likely to respond if I contacted them directly! This will be further discussed during forthcoming phone calls but indicates one of the challenges involved in maintaining a PPIE panel of young people. Before conducting further PPIE activity, I shall seek further advice from services that have a track-record in maintaining an active PPIE panel of children and young people (outside of the the SCH Trust).

9. Submission Date:

This PPIE project will inform an application for the NIHR Clinical Doctoral Research Fellowship in April 2023.

Appendix:

Appendix 1: Initial information sheet

Sheffield Children's 
NHS Foundation Trust

Falls and Dynamic Stability in Young People with Cerebral Palsy: Patient and Public Involvement and Engagement Information Sheet

Project Background:

As a physiotherapist working in the gait laboratory (a service that assesses how young people walk), one of the most common barriers to walking that young people with cerebral palsy talk about is balance. Research supports this observation and suggests that falling and dynamic stability - the ability to maintain balance whilst walking - is a significant problem. Despite this, we still don't know very much about the effect that falls and impaired stability have on the lives of young people, how it relates to other aspects of their walking ability, or how they can be best measured. To help develop research in this vital area, we need to hear from the young people with experience of living and walking with CP. This type of activity is called patient and public involvement and engagement (PPIE).

What is the objective of the PPIE?

PPIE helps ensure that research is as relevant as possible to the people it is intended to benefit. As such, the purpose of the workshops is to confirm whether falls, fall avoidance and walking stability are priorities for young people with CP. They will also explore the understanding of key concepts associated with falling, balance and stability. Contributors will be encouraged to share experiences of falling, as well as providing feedback on a questionnaire designed to identify issues with falls and balance. The practicality and potential use of dynamic stability (or balance) measures will also be discussed.

What will it involve?

Two virtual workshops will be organised at a time that best suits the group. Specific activities will need to be completed prior to the workshops, details of which will be shared no less than a week prior to the event. The workshops will be approximately two hours long, during which contributors will be expected to participate in group discussions and share their own experiences and ideas. Contributors will be encouraged to stay in contact following the workshops by whatever method works best for the group (e.g., email, Twitter), allowing for updates and ongoing conversations as the project develops. Contributors will also be involved in finalising the plain English summary of the final proposal.

How will I access the workshops?

The workshops will be hosted online with a virtual conference platform, such as Google Hangouts or Zoom. Details and invitations will be sent out by email. The best experience will be through the use of a home computer or laptop with reliable internet access and a webcam. Experience of safe internet use is a must. There are numerous guides on how to stay safe on the internet for parents and young people, including those available at: www.saferinternet.org.uk.

A smart phone with internet access and camera (facing the user) may also be used if a computer or laptop are not available.

Practicing how and where to access the virtual workshops is recommended before the actual date, which the project lead would be happy to help with if required.


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What's in it for me?

This is an opportunity to have your say and gain valuable experience of how research is designed and developed. All contributors will be provided with a certificate to recognise their input.

As a thank you for their time and input, contributors will also be provided with £60 in high street vouchers. This includes the workshops and comments on the final proposal and plain English summary. £5 in remote working costs will also be provided.

Are there any risks?

The discussions will be chaired by an experienced health professional employed by the Sheffield Children's Hospital. Respectful, non-judgemental and open conversation is expected of all contributors. It is possible that discussions will involve sensitive topics, such as social embarrassment, or recalling upsetting experiences, and for this reason we advise that each contributor has someone nearby they know can support them if they become upset.

The wellbeing of all contributors is of the utmost importance, so if any information is disclosed that gives cause for concern to the health of that individual, or any other, then the facilitator will have a duty to share this information with relevant bodies in order to protect that individual.

Any PPIE activity is likely to involve third-party software, social media and online platforms, which have their own safety, privacy and confidentiality policies and practices. It is worth familiarising yourself with these, as no platform is completely risk-free or secure. It is worth repeating that experience of safe internet use is essential.

The workshops themselves will be video recorded for use by the project lead to recall conversations and contributions. This video will be stored securely on Sheffield Children's Hospital NHS Foundation Trust servers and deleted after completion of the PPIE (approximately one year).

Any contribution is voluntary and you would be free to withdraw at any time without giving a reason.

How can I find out more?

I am happy to answer any questions you have. Please don't hesitate to get in touch. I work clinically, so if I am unable to respond immediately then I will reply at the next available opportunity.

Contact details:

Project lead:

Alan Royle,
Advanced Physiotherapist, Gait and Motion Laboratory, Ryegate Children's Centre, Sheffield Children's Hospital
NHS Foundation Trust

Email: alan.royle@nhs.net

Landline (gait laboratory): 0114 271 7629

Mobile: 07772319882

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Appendix 2: Consent Document



Falls, Fall Avoidance and Walking Stability for Young People With Cerebral Palsy: Public and Patient Involvement and Engagement (PPIE) Consent Form

The following consent form is for use with the information sheet of the same title (Version 2). Please ensure that you have read this information sheet and asked any questions you have of the project lead, who's contact details can be found at the bottom of the document. If you are happy to participate please complete and sign the consent form below. For those under the age of 16 the document should also be counter-signed by a parent or legal guardian.

	Activities	Initials
1	I confirm that I have read the attached information sheet (Version 2) and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the project is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself.	
3	I agree to the virtual workshops being video recorded (any copies of which will be kept securely on Sheffield Children's Hospital NHS Foundation Trust servers)	
4	I agree that anonymised quotations may be used in publications and on social media.	
5	I agree that data collected may be published in anonymous form in academic books, reports or journals.	
6	I agree that the Sheffield Children's Hospital NHS Foundation Trust research department may contact me in future about other PPIE projects.	
7	I agree that the project lead may retain my contact details to provide me with feedback.	
8	I understand that there may be instances where during the course of the project information is revealed which means that the staff members will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	
9	I agree to take part in this project.	

Data Protection

The personal information we collect and use to conduct this project will be processed in accordance with data protection law.

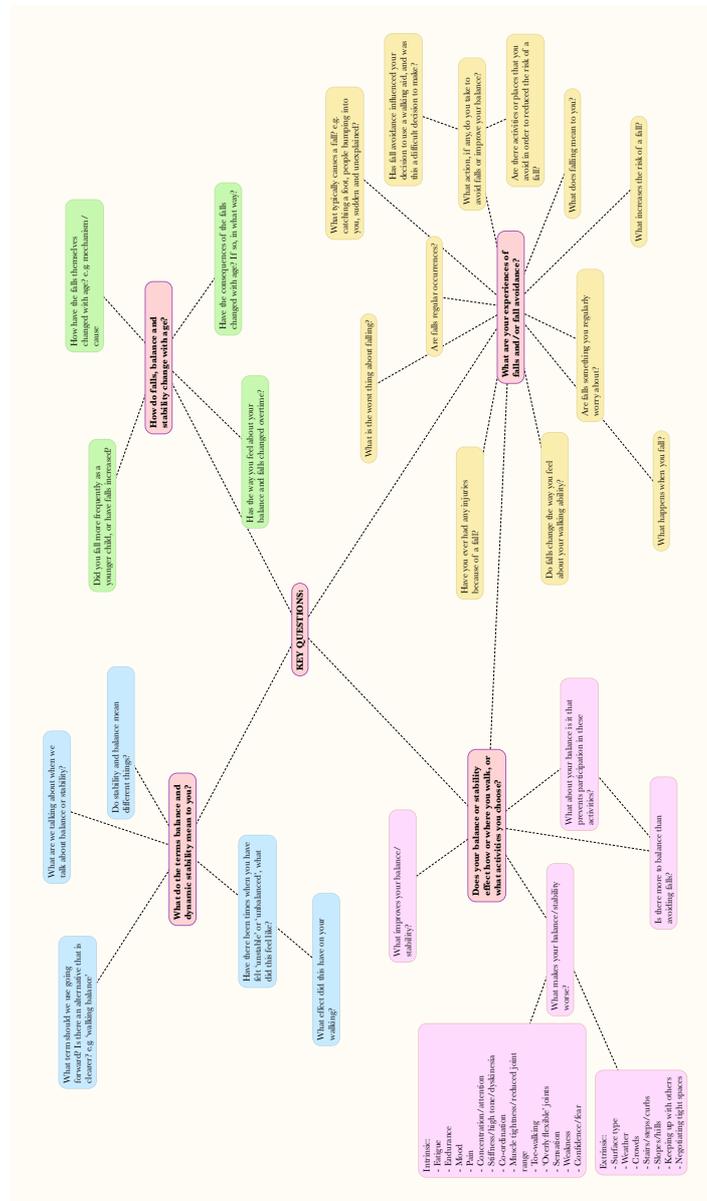
Name of Public Contributor¹ Signature Date

Name of Parent/Legal Guardian Signature Date

Name of the person taking consent Signature Date

PPIE consent form v.1
Last updated: June 2021

Appendix 3: Topic Work-board



Appendix 4: Table of Costs

Item	Cost	No.	Sub-total
High street vouchers (honorarium rates)	£60	6	£360
Remote working costs	£5	6	£30
Total			£390