**Exploring delivery of 24-hour Postural Management**

Laura Canning and Dr Lisa Bunn

[Laura.canning@nhs.net](mailto:Laura.canning@nhs.net), Learning Disability Service, Devon Partnership Trust, Devon, United Kingdom

Peninsula Allied Health Centre, Plymouth University, Plymouth, United Kingdom

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*“I certify that all material in this dissertation which is not my own work has been identified and that no material is included for which a degree has previously been conferred on me”.*

**Abstract**

**Purpose:**

This study explores the enablers and barriers, from the perspective of caregivers supporting adults with Profound and Multiple Learning Disabilities (PMLD), in delivering 24-hour postural management programmes. Where communication and comprehension barriers exist for adults with PMLD, first-hand accounts of experience are not feasible. Therefore, the caregiver experience seems a pragmatic population to explore, whilst acknowledging the biases of this second-hand perspective.

The primary aim of this study is to explore factors impacting delivery of 24-hour postural management. Understanding these will allow clinicians to modify their practice, in turn, reducing costs associated with secondary complications and improving quality of life.

**Methodology:**

This qualitative study employed semi-structured interviews to enable exploration of new themes. Participants were recruited through the local NHS trust using purposeful sampling strategies, including both paid and informal caregivers, to achieve maximum variation. A framework analysis approach was used to organise, classify and evaluate key themes emerging from the data.

Ethical approval for this study was awarded by the Health Research Authority (242714) and the Faculty of Ethics at the University of Plymouth.

**Results:**

Six caregivers, informal and paid, demonstrated their enthusiasm and willingness to discuss experiences of 24-hour postural management giving a balanced view of both enablers and barriers. A number of clear influencing factors were identified and can be grouped into four sets. The central themes are considered client factors including choice, participation and physical health. The remaining themes centre upon carer, professional and commissioning factors with a strong emphasis on the need for effective communication, specialist assessment and accessible services.

**Conclusion:**

Thematic analysis highlights consistency amongst caregiver experiences so can be used to inform the development of local clinical action plans. A number of actions including introduction of specialist postural management physiotherapists and bespoke training packages could be implemented, where clinically reasoned, allowing clinicians to modify their practice and enhance caregiver engagement.

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**1.0 Introduction and Literature Review:**

Adults with profound and multiple learning disabilities (PMLD) are among the most disabled individuals living in our community (Mansell, 2010). A profound learning disability estimates an intelligence quotient below 20 severely limiting understanding, posing significant barriers to communication and comprehension (Mansell, 2010). Furthermore, individuals present with other complex co-morbidities including epilepsy, dysphagia and autism (Heslop *et al*. 2013).

Adults with PMLD often present with long-term neurological conditions, resulting from damage to the nervous system, significantly affecting the individual and their support network (DOH, 2005). These conditions may be considered stable but individuals can present with severe distortions in body shape, particularly affecting the spine and hips, which worsen with ageing (Mansell, 2010). These distortions reduce quality of life and cause problems with fundamental activities such as personal care, eating and drinking (Hobson, 1992). Failure in their management will often result in secondary complications including pressure ulcers, pain and respiratory infections, all increasing cost and burden to the person, their caregiver and the NHS (Mansell, 2010).

It is often assumed that body shape distortion and contracture development is inevitable, however, it can be prevented with specialist positioning (Heslop *et al*., 2013). Furthermore, NICE (2012) highlight, in the spasticity management guidelines for under 19’s, that protecting body shape and posture is vital to prevent pain and contractures, whilst enhancing skill development and function. 24-hour postural management aims to restore and maintain body shape, structure and function whilst enhancing quality of life, maximising vital functions and promoting participation (Lukersmith, 2012). With this in mind, provision of bespoke, comprehensive 24-hour postural management programmes are recommended for those at risk of postural deformity (Crawford and Stinson, 2014). Assessment and intervention should consider provision of specialist equipment for use in sitting, lying and standing to maintain symmetry, accommodate deformity and protect individuals from further deterioration (Public Health England, 2018). All NHS bodies should ensure they provide specialist services, focusing on protection of body shape, to adults with PMLD (Mansell, 2010). Despite this, it has been recognised, that services for adults with PMLD, remain insufficiently developed to effectively manage postural distortions with inconsistencies in practice across the UK (Public Health England, 2018).

Currently literature focussing on 24-hour postural management is limited, with an inadequate evidence base to inform service design nationally. Robertson *et al.* (2016) conducted a systematic review of 23 studies investigating postural management for people with learning disabilities. Many of the studies evaluated were anecdotal, which, considering the potential variability in needs may not be transferable. Three of the studies focussed on positioning, however, key stakeholders instigated these studies introducing bias. Furthermore, many of the studies reviewed focussed on children rather than adults. When comparing child and adult populations, arguably, the influence of caregivers, the environment and ethical considerations regarding capacity may all impact on the size and quality of this evidence base. As clinicians, regardless of age, we need to explore influencing factors to ensure we are delivering an effective, high quality service.

Within the existing literature, despite the focus on children, there are factors that can be transferred into the adult population including the need for caregiver education (Goldsmith, 2000; Humphreys, 2010; Humphrey’s and Pountney, 2006; Maher *et al*., 2011) and the value of clear communication between clinician and caregiver (Maher *et al*., 2011). We must also consider that children with complex disabilities will become adults with disabilities therefore intervention should continue to prove effective as a person ages (Gough, 2009). There are also significant differences, for example, many adults with PMLD will be supported by paid caregivers rather than family members. Paid carers may be contractually obliged to deliver certain elements of care for which funding may vary. In addition, given the age range of the adult PMLD population, individuals may have lived in institutional care for a prolonged period. Deformities may be well established and 24-hour postural management may be a new concept to caregivers and the adults they support. Therefore, studies focussing on children may not be truly representative of the adult population and, as communication and comprehension barriers exist for adults with PMLD, exploring the adult caregiver experience remains a pragmatic population to explore.

**1.1. Study Aim:**

The aim of this study is to explore the factors impacting on delivery of 24-hour postural management, from the perspective of caregivers supporting adults with PMLD. New knowledge may allow clinicians to modify their practice and address limiting factors. This could in turn enhance caregiver engagement, ensure equipment and therapy is used to its best effect, thus reducing secondary complications and associated costs. Ultimately, improving quality of life.

To achieve this aim the primary objectives of this study are:

1. To explore the factors underpinning perceived enablers and barriers and how this impacts delivery of a 24-hour postural management programme.
2. To discuss experiences of collaboration with clinicians and how this influences enablers and barriers.
3. To use data collected from semi-structured interviews to inform a clinical action plan to enhance caregiver engagement with 24-hour postural management.

The nature of recruitment for this study facilitates additional sub-group analysis; comparing themes derived from paid and informal caregivers.

**1.2 Literature Search Strategy:**

The research question was developed using the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) format (Cooke, Smith and Booth, 2012). This identifies key points whilst guiding the search process, providing more advanced thinking when compared with other tools such as Population, Intervention, Comparison and Outcome (PICO) format (Cooke, Smith and Booth, 2012). Table 1 illustrates the search terms and databases used.

Table 1: Application of SPIDER within literature search.

|  |  |  |  |
| --- | --- | --- | --- |
|  | Application to research question | Search terms | Databases |
| Sample | Caregivers | ‘carers’, ‘caregivers’, ‘family’, ‘parents’, ‘personal assistants’, ‘PA’, ‘1:1’ ‘support workers’, ‘PMLD’, ‘PMID’, ‘Profound and Multiple Learning Disabilities’ | CINAHL, MEDLINE, PUBMED and The Cochrane Library, |
| Phenomenon of interest | Attitudes associated with delivery of  24-hour postural management | ‘24-hour postural management’, ‘24-hour postural care’, ‘positioning’, ‘experiences’, ‘attitudes’, ‘behaviours’, ‘barriers’, ‘enablers’, ‘delivery’, ‘implementation’ |
| Design | Interviews | ‘interviews’, ‘focus groups’, ‘semi-structured interviews’, ‘face to face interviews’. |
| Evaluation | Themes extracted from transcripts |  |
| Research type | Qualitative | Qualitative,  Framework Analysis |

**1.3 Rationale and Background:**

Given the need for delivery over 24-hours, clinicians work closely with caregivers to implement postural management programmes. Crawford and Curran (2014) highlight that carer feedback and communication with caregiver’s is crucial in the development of postural management services. Alternatively, Lawler, Taylor and Shields (2014) report increased therapeutic success, overall, with effective caregiver involvement throughout decision-making processes. With application of the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001), to ensure a holistic approach, we need to develop a comprehensive understanding of the relationships between complex physical health, support network, social environment and how this influences 24-hour postural management (Hardy, 2004). Understanding these relationships supports clinical decision-making allowing clinicians to promote enablers and limit the impact of barriers (Hardy, 2004). This emphasises both the need for caregiver feedback to develop services in the first instance and on-going collaboration throughout decision-making processes.

**1.3.1 Service development:**

A number of studies have explored the views of caregivers and professionals with an aim to develop and review current service provision. Using a survey design, Crawford and Curran (2014) investigated the clinical impact of a newly developed 24-hour postural management service for adults with learning disabilities. Despite using a small number of open questions, Crawford and Curran’s (2014) survey design primarily used close questions requesting respondents to rate their experiences without exploring their reasoning. This may impact how results are interpreted and applied within the service evaluation, given limited context gained. In contrast, Humphreys and Pountney (2006) developed an Integrated Care Pathway following discussion with clinical staff and caregivers using a focus group design. Despite their methodological differences, both studies reiterate the need for effective collaboration with caregivers during development of management programmes. Furthermore, given the communication needs of the service users involved, purposeful subject recruitment focussing on caregivers, was implemented across both studies. It is pertinent to note, Crawford and Curran (2014) solely explored experience of working with Occupational Therapists. This role is challenged with existing literature, Poultney *et al*. (2002) argues that physiotherapists have an integral role in the promotion and maintenance of posture, whereas, Mansell (2010) recommends a multidisciplinary approach to optimise postural management, considering the complexities of the individuals involved. Any study focussing on a single profession, given professional expertise and possible limitations, may not be representative of, or transferable across, other postural management services.

In addition to effective communication with caregiver’s, Humphreys and Poultney (2006) highlight the need for specialist clinicians working in a dedicated service. This is supported by Humphreys (2010), who not only suggests that generic clinicians do not have the skills or expertise to provide postural management programmes, but also identifies this as a risk across services. Specialist assessment, by a dedicated clinician, facilitates effective application of the ICF (WHO, 2001) by enhancing identification and comprehension of relationships between each component. Understanding these relationships supports clinical decision-making limiting the impact of potential barriers and reducing risk (Hardy, 2004). Despite Humphreys and Pountney (2006), reporting that their pathway was designed to consider the needs of children and adults, there were very few subjects included with experience of working with adults with PMLD. This is pertinent considering potential variations in commissioning and service accessibility. Writing an Integrated Care Pathway (Humphreys and Pountney, 2006) using experiences from children’s service cannot be applied to adults for who services may vary.

A number of other studies have explored child caregiver experiences of 24- hours postural management to develop a clinical action plan. These studies focus on children, both with and without a learning disability, most focussing on a single aspect of postural management rather than over 24-hours. Using qualitative research methods, Goldsmith (2000) and Humphreys (2010) capture family experiences of positioning using sleep systems, whereas, Hutton (2008) and Maher *et al*. (2011) explored the attitudes of staff delivering positioning programmes within a school setting. The outcomes presented demonstrate a strong focus on improving professional communication, developing caregiver knowledge and understanding the needs of the service user. This further demonstrates the importance of comprehending the relationships between family, environment and intervention allowing barriers to be addressed and enablers to be promoted.

**1.3.2 Communication:**

Communication is widely explored across the existing literature, highlighted as both a barrier and enabler from the perspective of caregivers in delivery of postural management. A number of communication forms are discussed including verbal communication (Humphreys, 2010; Maher *et al*., 2011), the development of written programmes (Maher *et al*., 2011) and the development of clinical frameworks for communication between professionals (Hutton, 2008; Castle, Soundy and Stubbs, 2014). Humphreys (2010) is the only study to discuss the need to communicate and explore communication with the service user receiving postural management. They report this as an area in need of improvement with findings emphasising the possibility of communication despite complex difficulties. However, they do not discuss how this may be impacted by level of comprehension rather than physical difficulties. A profound learning disability estimates an intelligence quotient below 20, severely limiting understanding and comprehension (Mansell, 2010). This poses significant barriers to communication within both child and adult populations so researchers are reliant on a second-hand perspective.

Maher *et al*. (2011) found that open and regular communication between clinician’s and caregivers with programmes documented in writing enables effective delivery of postural management within a school setting. Crawford and Curran (2014) support this emphasising that written guidance provided by clinicians is deemed an important factor, by caregivers, enabling delivery of postural management. This highlights some consistency across both children and adult services given the populations explored in each study, however, neither study detail how information should be presented. Public Health England (2018) recommends that simplified postural management guidelines should be shared with caregivers, whilst Houts *et al*. (2006), highlight that use of pictures improves adherence to health instruction as they demonstrate spatial relationships. For those with the most complex postures it may be unsafe and unsuitable to simplify postural recommendations especially in respects to activities in which correct positioning will improve safety (Hobson, 1992), for example use of seating during meal times. Therefore, versatility within written documentation to ensure effective delivery is important and it seems reasonable that written communication should not follow a defined format. This should instead consider body structure, function, activity, environment and the needs of the caregiver.

**1.3.3 Developing caregiver knowledge:**

In contrast to the studies examined focussing on families and paid caregivers, Page and Clayton (2016) explored the skill set and knowledge of postural management within the nursing profession. This study used qualitative methods to collect information from eleven student nurses and found a lack of standardisation, confidence and clarity in relation to postural management. This study recruited nursing students with a variety of experience and from different specialist areas including Learning Disability, Adult and Paediatric. This may introduce bias as a third year Paediatric nurse may have more exposure to postural management, or at least individuals with complex physical disabilities, compared with a first year adult nurse. This study highlighted the need for specialist education and an increased awareness of highly complex physical disability to transfer knowledge and skills between populations and settings.

Similarly, Castle, Soundy and Stubbs (2014) found that healthcare professionals working in learning disabilities services lack confidence, awareness and skills associated with making onward referrals to specialist postural management services. They used a mixed methods approach over two phases, including a survey to collect quantitative data with semi-structured focus groups to enhance the data collected. They concluded that a training package should be designed and delivered to address decreased confidence. These findings are of importance as they indicate a likely deficit in knowledge across professional groups, yet as clinicians we expect caregivers to take responsibility for delivery of 24-hour postural management programmes within the home. Without robust national guidance, services are unlikely to provide a consistent approach in respect to training and information offered. Given the findings reported by Page and Clayton (2016) and Castle, Soundy and Stubbs (2014) a strong reliance on caregivers, who unlike the subjects discussed above, may have no formal training could impact the effectiveness of intervention directly effecting the service users.

Delivery of training packages to caregiver’s, to enhance delivery of 24-hour postural management, is supported within existing literature (Goldsmith, 2000; Humphreys, 2010; Humphrey’s and Pountney, 2006). It is suggested within each study that, understanding the factors influencing delivery of 24-hour postural management allows tailored training packages to be delivered to caregivers, improving caregiver knowledge of what and when support is required. Furthermore, Goldsmith (2000) highlight that parents need to be considered the expert in their child’s needs. It is pertinent to note, however, that adults with PMLD often live in residential or nursing care homes with, from experience, a great variation in workers therefore this expertise may be lost. This, therefore, reiterates the need for high quality, specialist-training packages.

Hotham *et al*. (2017) explored the effectiveness of a six-week postural management training programme delivered to parents and school staff, the aim of which was to increase knowledge, understanding and confidence. Using a questionnaire pre and post training, with additional focus groups and interviews post training, Hotham *et al*. (2017) found that practical elements, especially experiencing postural management themselves, were deemed most effective. Overall they report an improvement in knowledge, understanding and confidence, even though, not all of those attending the training participated in the review. One could argue that this study achieved its aims and demonstrated the training programme in question had a positive impact, however, it does not capture the influence that training had on delivery of postural management. We would need to assume that there is a correlation between improving knowledge and improving actions, as the outcome of this study does not identify the impact of the training programme on the care received by service users.

**1.3.4 Understanding the needs of the service user:**

The general health of those supported is a recurrent theme throughout existing literature and is considered a potential barrier to the delivery of positioning programmes for children (Goldsmith, 2000; Humphreys, 2010; Hutton and Coxon, 2010). It is also well documented that adults with PMLD have complex health needs increasing the probability of hospital admission (Mansell, 2010). Therefore, we must be mindful that those individuals, of any age, presenting with significant distortions in body shape, are most likely to also present with co-morbidities increasing caregiver demands both physically and psychologically (Venkateswaran and Shevell, 2008). This is supported by Hutton and Coxon (2010) who described the emotional impact, experienced by teaching staff, when supporting a child with complex physical disabilities at school. They shared their anxieties specifically about causing the child pain. It should also be considered that, despite potential similarities between adult and child populations in respects to complex physical health needs, Pierce *et al*. (2010) suggest that physiological effects of ageing impacts on spasticity and contracture development. This therefore influences the clinical reasoning underpinning delivery of 24-hour postural management as one could propose that implementing postural management in the adult population is vital to prevent further deterioration.

Humphreys (2010) used semi-structured interviews to review posture and sleep for children with cerebral palsy. Similarly to Hutton and Coxon (2010), they highlight pain as a significant barrier to 24-hour postural management, emphasising the importance of this given the consequences of sleep deprivation. Unlike many of the studies discussed, Humphreys (2010) explored the views of the child, their parents and the clinicians to develop clinical recommendations to give more holistic viewpoint. These recommendations advise that clinicians should routinely use the ICF to plan and predict effectiveness of outcomes whilst making participation the focus of intervention, however, the child must be involved in making those plans. It highlights the importance of seeking the child’s viewpoint in respects to self-esteem and draws a correlation between increased self-esteem and reduced vulnerability to abuse (Humphrey’s, 2010). In contrast, Goldsmith (2000) emphasise the need for clinician’s to better support parents, rather than the child, acknowledging them as experts in their children’s needs. This study demonstrates a strong focus on body, structure and function highlighting that the key to successful intervention is for caregivers to understand general distortion tendencies within a child’s body. Each of these studies explores positioning in lying and the disparity between the holistic focus of these two studies could be associated with the clinical changes over the ten years between each study. Furthermore, Goldsmith (2000) is known to have a vested interest in 24-hour postural management and the commercial market, introducing bias.

Maher *et al*. (2011) used a survey design with purposeful sampling to explore the factors affecting postural management within a special school setting. They found a number of environmental factors impacted delivery of postural management during the school day including insufficient time and availability of equipment. With this in mind Maher *et al.* (2011) highlights the need for clinicians to integrate programmes into the child’s daily timetable. Alternatively, Hutton (2008) used individual and group interviews to explore the views of teaching staff in the delivery of postural management programmes for children in mainstream schools. Despite the variation in settings, this study also found environmental factors impacting on delivery of intervention including the size of equipment and use during lessons impacting relationships with peers. Hutton (2008) also found a lack of understanding contributes to a rigid compliance with programmes, often at the detriment to the child. Unlike Maher *et al*. (2011), Hutton (2008) explored children within a mainstream school, therefore, we must consider the child’s ability to consent and voice concerns regarding practice compared with children in a special school setting. Arguably, recommendations to integrate programmes into daily timetables (Maher *et al.*, 2011) may promote rigid compliance and encourage the barriers highlighted by Hutton (2008). Each of these studies focuses on a school setting, which may be influenced by funding, access to equipment, local drivers and staff training. This environment, ultimately, is not representative of the general community setting and many aspects of 24-hour postural management may not be represented in the school day.

All of the studies explored use qualitative methods to better understand delivery of postural management. Qualitative research methodologies allow us to build a holistic picture of a human conundrum (Srivastava and Thompson, 2009). Despite the arguable loss of scientific rigour, which may be more associated with quantitative research methods, allowing subjects to openly communicate their own experiences and reflections uncovers valuable meaning in clinical research and practice (Schutz, 1994). Therefore, qualitative research methods were adopted, within this study, to explore the enablers and barriers, from the perspective of caregivers supporting adults with PMLD, in delivering 24-hour postural management programmes.

**2.0 Methodology:**

**2.1 Principles of chosen methodology:**

This qualitative study explored perceived enablers and barriers experienced by caregivers using a framework analysis approach to identify themes. It compared data collected from six semi-structured interviews lasting approx. one hour (DiCicco and Crabtree, 2006). A pilot was conducted with an initial participant, who had volunteered to participate within the study, to ensure that the framework used for interviews (Appendix 1) addressed the aim of the study. The purpose of the pilot was to ensure clarity, readability, timing and ensure understanding of the scenario presented to the caregivers. This pilot was also used to ensure effectiveness of data collection methods used. It successfully demonstrated that the interview design addressed the aim of the study with no changes made subsequently so, this transcript, was included within the data analysis.

Within existing literature, interviews are widely used to explore delivery of 24-hour postural management (Goldsmith, 2000; Humphreys, 2010; Hutton 2008). These study’s use semi-structured interviews within paediatric settings, which is not reflective of this clients group, Goldsmith (2000) and Humphreys (2010) solely focus on use of sleep systems therefore any pre-existing proformas could not be used. The use of semi-structured interviews in each of these studies supports exploration of perceptions during extraction of themes (Low, 2013). Using this method allows the interview’s pace to be modified to the needs to the participant, particularly important to those providing high levels of care to another (Corbin and Morse, 2003). As previously highlighted researchers need to consider the emotional impact of supporting an individual with complex disabilities (Hutton and Coxon, 2010).

Copies of a fictitious personal 24-hour postural management programme were used to help direct the interviews in meaningful way (Appendix 2), this was designed to incorporate all postures adopted by an individual over 24-hours (Crawford and Stinson, 2014). The positioning depicted, although may not be experienced by all potential participants, was chosen as this reflected local practice and equipment frequently used. Lee *et al.* (2010) reports that, when unable to use direct observation, use of scenarios can promote understanding by evaluating how subjects react to a realistic scenario in which they can imagine themselves, making this a useful adjunct within interviews. This is supported by Schutz (1994), who also highlights the need to develop an effective partnership with participants to promote open discussion about their own experiences. On the other hand, a well-established, existing relationship between researcher and participant, is likely to introduce bias during interviews (Wong, 2008). Despite this, making subjects feel their views are respected and offering signposts to external support may subsequently reduce bias (Humphreys, 2010). This is supported by Johnson (2002) who also, recommend that subjects should be given control over how points are discussed. This may prove difficult when using any structure within an interview, however, giving participants the opportunity to describe their experiences without direct questioning could enhance feeling of control.

Alternative research methods were considered to meet the aims and objective of this study including survey and focus group designs. Whilst surveys can, in a timely and cost effective way, provide high amounts of data across a wider population there is risk of misunderstanding and the response rate is often poor (Robson, 2002). In contrast, interviews allow individuals to give meaning for their perceptions, therefore, have advantages over surveys in collecting data regarding attitudes and experiences (Low, 2013). In the context of the proposed research study we must be mindful of the vulnerability of adults with PMLD and supporting their caregivers. If for example, information was divulged indicating a safeguarding concern, use of surveys would not allow identification of those at risk.

Furthermore, one could argue that use of focus groups provide the opportunity to collect quality data about experiences. They allow participants to formulate and build on their responses, considering what others have said, whilst providing the researcher opportunity to extract more detail (Wong, 2008). However, within focus groups there remains a strong risk of bias from the presence of a dominant participant (Wong, 2008). It is anticipated that power dynamics could introduce bias into this study as, using a maximum variation sample, individuals with strong views could dominate others. This may have greater impact if individuals work together or if value was attributed to a participant’s experience. Also, it is anticipated that discussion could encourage caregivers to raise potential safeguarding concerns and use of focus groups would impact anonymity. This is an integral ethical consideration in the proposed study therefore focus groups would not be suitable for data collection.

**2.2 Exclusion/Inclusion criteria:**

Caregivers were included if they:

* Had present experience of implementing a positioning programme of lying, sitting and/or standing for adults with PMLD over a 24-hour period.
* Were an English speaking full or part time worker, paid or informally caring, related or not to the adult with PMLD.
* Were delivering a postural management programme developed in collaboration with a physiotherapist working in the local NHS Trust as named within the ethics application.

Individuals were excluded if they were:

* Friends with/related to but not providing care to adults with PMLD.
* Caregivers delivering postural management programmes with children under 18.
* Caregivers with historical experience of implementing positioning programmes but no current experience. This is to reduce distress if the adult has passed away or bias if local practice has changed.
* Caregivers working with adults who have complex physical disabilities but diagnoses not classified as PMLD.
* Not offering consent for interview audio to be recorded as this will impact on data analysis.
* Unable to converse (understand or speak) English language for the purpose of providing informed consent and interview responses.

**2.3 Recruitment:**

The identification of participants was derived from the clinical practice of local physiotherapists’ enabling purposeful sampling with maximum variation; including paid carers from different funding streams, informal caregivers, family members and those with a range of views. Identification of adults with PMLD on their caseload with a prescribed 24- hour postural management programme, allowed secondary identification of their caregivers. Participants were approached independently of their organisation to reduce bias associated with a “management down” approach to recruitment. The physiotherapists who facilitated recruitment were not be part of the research team but were actively involved with the client’s existing physiotherapy interventions.

Once versed in the research study's inclusion and exclusion criteria, these ‘recruiting physiotherapists’ identified potential participants in the course of their working days and manually delivered information packs, prepared by the researcher, to the potential participants. Information packs comprised of a letter of invitation to the study addressed to ‘the potential participant’, an information sheet (Appendix 3), a consent sheet template (Appendix 4) and contact details for the research team. The consent form was provided for review by the subject, but completed immediately prior to commencement of the interview. This allowed witnessing of signatures by both parties.

For paid providers a letter to their employer (Appendix 5) was also available providing details of the study and the impact on their employees. This was agreed with the Health Research Authority Ethics panel as it was felt that employers may hold negative views towards this study if they perceived this as an assessment of the service they provide. This could therefore influence participants desire to participate, therefore, reassurance was provided to employers in writing to minimise impact on recruitment. All potential participants contacted the researcher directly and were screened against the inclusion/exclusion criteria by the researcher with verbal consent established. During this initial contact a convenient interview time, date and location was scheduled. Figure 1 demonstrates the recruitment flow of participants from initial contact to data analysis.

*Figure 1.* *Recruitment flow of participants throughout study*

8 potential participants contact researcher after initial recruitment phase

8 potential participants contacted by researcher to discuss study further

2 potential participant withdrawal due to commitment

25 study information packs distributed

6 participants consent and continue study with no withdrawals

Interviews arranged with 6 participants identified

**2.4 Sample:**

Six voluntary participants, provided written consent prior to each interview, constituted the sample. The low number of applicants reflects the anticipated small population size from which this study could sample participants. Whilst the total population size of caregivers known to the trust remains unknown to the researcher, it appears that there was relative support from the community for this project especially given that no reimbursement was offered for participation. The suggestion that relevant themes only need to appear once to be considered within analysis (Ritchie *et al*., 2003) supports the value of findings from this sample despite its size.

**2.5 Data Collection:**

Participants were offered a choice of location given no reimbursement was offered and to address potential risks associated with power dynamics (Johnson, 2002). It was anticipated that some caregivers might wish to meet in a home environment or location convenient for work. However, it was agreed that it would not be appropriate to interview paid carers within their workplaces, as these are typically their client’s home (Low, 2013). Interviews were offered in local meeting facilities, namely NHS meeting rooms, ensuring comfort, privacy and safety could be maintained during interviews. In consideration of audio recording quality, confidentiality and privacy, noisy and crowded venues (such as cafes) were not used. With strict accordance with the local lone working policy, three interviews were undertaken in the participant’s own home and three interviews were undertaken in an agreed office location on a NHS site.

Audio data was collected using a digital audio recorder allowing recordings to be stored and saved securely in encrypted digital files. This is a low cost method of recording with minimal intrusion and is more easily pseudo-anonymised than video recordings. To enhance validity and reliability, verifying interpretation of data, field notes were collected by the researcher documenting non-verbal cues (Miczo, 2003; Hoey, 2014). Recordings were transcribed verbatim to preserve meaning and to reduce risk of misjudgements that may come from summarising data (Low, 2013). This maintained transparency and rigour, whilst ensuring that individual views remained embedded within the transcripts (Gale *et al.,* 2013). Only audio data risking revelation of a participant’s identity or that of any related individual was omitted from the transcripts, in line with the Common Law of Confidentiality and the General Data Protection Regulation (EUGDPR, 2018). It is recognised that self-transcription can prove time consuming, however, this allowed the researcher to become familiar with the content and facilitated data analysis (Srivastava and Thompson, 2009). Once audio recordings were transcribed these were securely digitally deleted.

**2.6 Data Analysis:**

Framework analysis is commonly used in health research for the thematic analysis of semi-structured interviews (Gale *et al*., 2013). The aim of this study is to explore attitudes to positively influence and direct improvements in clinical practice, unlike Grounded Theory, the aim was not to generate social theory or to test the authenticity of the themes (Patton, 2002). Framework analysis allows comparison of key themes across the data set whilst ensuring the individual’s views remain embedded in the findings. In addition, the structure employed and systematic review of data using a framework promotes transparency and rigour (Gale *et al*., 2013). This is opposed to both content analysis, which is deductive with categories defined before data collection (Robson, 2002), and Grounded Theory which constantly moves back and forwards comparing data with codes to identify consistent themes and relationships (Foley and Timonen, 2015).

During the early stages of analysis, an inductive approach was adopted to support extraction of themes directly from the data collected (Gale *et al.,* 2013). A framework design facilitates theme extraction as the use of charting supports pattern recognition, whilst maintaining a clear audit trail to ensure transparency (Gale *et al*., 2013). Thereafter, the comparison of established themes across data sets and interpretation of potential relationships can be considered deductive (Patton, 2002). Again, use of the framework structure allows codes to be interpreted and contextualised effectively without losing meaning (Gale *et al*., 2013). In summary, framework analysis allows thematic analysis of transcripts whilst supporting comparison of key themes across the data set.

**2.7 Ethical Considerations:**

There are a number of ethical considerations with respect to the study participants and the adults with PMLD who will be discussed. Ethical approval was applied for and gained from the Health Research Authority and Health and Care Research Wales (HCRW) case number 242714. Additional ethical approvals were gained from the University of Plymouth and the relevant local NHS trust.

The subject design was chosen to maintain anonymity of participants and adults with PMLD. Participants were discouraged from using names of their clients/family/colleagues or referring to any identifiable details. Any personal identification data disclosed was screened out of transcription and thus eliminated from any further dissemination of findings. Arguably voice is identifiable however participants were not referred to by name or asked to introduce themselves. All recordings were stored securely on an NHS computer in password protected files, unavailable to any other person.

Specific consideration was given to the risk of participants conveying safeguarding concerns. Clear information was provided regarding consent, use of information and escalation of concerns. Similarly, if there was indication of poor practice, caregivers were referred back to the prescribing physiotherapist for a review of the respective programme. This is clearly documented in the participant information provided (Appendix 3).

Inclusion of paid caregivers working for large care providers, may offer a unique set of biases not common to informal caregivers (e.g. bias not to disclose bad practice, not to disagree or divulge barriers involving their own abilities for fear of their employment). Furthermore, caregivers may feel obliged to participate if study recruitment is cascaded down from management. Caregivers were approached independently of their organisation and participants assured that their discussions would remain confidential (with the exception of where safeguarding issues are raised). Furthermore, to ensure no negative impact on paid caregivers, from the perspective of their employer, additional correspondence was made available to provide further information.

Given the complex physical health needs of adults with PMLD, caregivers may currently be providing postural management with PMLD who are at risk of premature mortality or may have supported other adults in the past who have passed away. To mitigate risk of emotional distress that may ensue, information regarding support groups was prepared to be shared with participants and all participants were given the opportunity to stop the interview at any time. This was made clear at the start and any caregivers who are not currently delivering intervention, potentially due to client death, were not included. These actions were not necessary or required during data collection, however, it must be considered that any caregivers who felt that this was a particularly distressing subject may have chosen not to volunteer.

**2.8 Assessment and management of risk:**

There was a significant risk that the researcher was known to the participant, introducing bias. Humphreys (2010) generally felt that this specific bias could impact positively within a study, suggesting that a desire for change promotes recruitment when a study demonstrates direct benefits to clinical practice (Humphreys, 2010). One could dispute that enthusiasm for change alone could impact on reliability of findings. If caregivers wish to present an overtly positive view of their experience this would still prove valuable in exploring factors enabling them to implement 24-hour postural management. However, this would be acknowledged as a potential limitation given lack of insight into potential barriers.

There is low risk to the adults with PMLD who may be discussed. It is acknowledged that ascent is unlikely to be gained due to a pre-existing formal documentation of lack of mental capacity. However, with aims to improve services generally it could be considered that developing an increased understanding would be in an individual’s best interests (DoH, 2005).

Any further risks to the researcher and participant will be mitigated by strictly adhering to the researcher's clinical lone working policy (available via https://www.dpt.nhs.uk/resources/policies-and-procedures/safety/lone-working). The researcher is fully disclosure-baring service (DBS) checked and in possession of professional indemnity insurance (Chartered Society of Physiotherapy membership) as well as on the health and care professions council register (HCPC). Additional logistical risk and mitigation is outlined in Appendix 6.

**2.9 Data protection and confidentiality:**

Within this project data is treated with the maximum respect for the participant’s privacy in corroboration with the General Data Protection Regulations (EUGDPR, 2018). Given the nature of this study, placing caregiver’s at its centre, pseudonymisation was used to remove personally identifiable information whilst maintaining an individual link with the data, allowing re-association with original data. This was of particular importance, in exceptional circumstances, such as disclosure of a safeguarding concern (Kalra *et al*., 2006).

As previously discussed audio data and field notes were collected and saved securely in encrypted digital files. These were securely deleted and destroyed once transcription was completed. As the sponsor for this study, the University of Plymouth, acted as the data controller for this study and all research data, apart from voice recordings, will be kept for 10 years. This includes consent forms and transcripts, which were scanned and uploaded to secure folders on the University of Plymouth network with paperwork versions securely destroyed within NHS offices.

All original identifiable data was stored on an encrypted NHS device accessible by the researcher only and participants were entitled to withdraw until data analysis. This was clearly documented on the consent form (Appendix 4). Personal data needed to send interview schedule correspondence to participants was stored in such files and securely deleted upon the completion of data analysis. People requesting a lay summary of the research findings could do so at any time and do not have to be known participants - any requests via email or in person will be acted on as soon as lay summaries are available with personal contact details securely deleted immediately. Although participants were advised that they were unable to withdraw following data analysis, this access to information remained important to ensure trust was maintained with the study, in which, participants had invested time and personal views.

Given the nature of this as a MSc project the sole researcher was under supervision. This supervisor does not have access to the encrypted files without the permission of the clinical researcher. Permission to access personal identification data was agreed only in exceptional circumstances, such as the prolonged ill health of the research or termination of contract as a clinician or University of Plymouth student, at which point the research study would need to be completed or ceased by the supervisor.

**3.0 Results and Interpretation:**

Six caregivers demonstrated enthusiasm and willingness to discuss their experiences of 24-hour postural management, present and historical, offering both enablers and barriers. The interviews conducted met the aim and objectives yielding results, which enhance our comprehension of the factors impacting delivery of 24-hour postural management, from the perspective of caregivers supporting adults with PMLD. Field notes collected demonstrated each participant’s comfort and ease within the interviews supporting the integrity of the statements made by participants. There was a variation in context of the caregiving experience, for participants identifying as caregivers, as summarised in Table 2.

*Table 2: Summary of context of participant’s caregiving experience.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Role** | **Support Location** | **Funding Streams** | **Gender** | **Allocated**  **Pseudonym** |
| Parent | Home | Continuing Health Care | Female | Alice |
| Parent | Home | Continuing Health Care | Male | Ben |
| Parent | Home | Continuing Health Care and Local Authority | Female | Emma |
| Paid support worker | Supported Living | Local Authority | Female | Danielle |
| Paid support worker | Residential home | Continuing Health Care and Local Authority | Male | Charlie |
| Home deputy manager | Residential home | Local Authority | Female | Florence |

Caregiver variations, as summarised in Table 2, reflect the variability of the caregiving role in practice offering the potential to contribute a broader scope of barriers and enablers. Additional sub-group comparison of parent and paid caregivers could also prove valuable for clinicians when understanding their needs. An unexpected yet significant outcome of recruitment, was the interest expressed to participate from two parents of the same client. Both wished to be included within the study and given their independent views, they were sampled as two individual participants.

Following transcription, themes addressing the research question, were identified by underlining segments of text within each transcript. Margins were used to describe the content with a label on one side and additional contextual notes documented on the other. Transcripts were then reviewed together with common labels identified and allocated codes, which encapsulated all the ideas. Table 3 details the codes arising from the data collected, within each main group, and the descriptors used to help ensure themes were identified consistently across each interview. All transcripts were manually reviewed again against the table of codes, their associated descriptions and data extracted before charting within a framework matrix. Data collected in one place allowed identification of connections between participants and categories. Consequently, themes arising from the data collected were categorised into four main groups client, carer, professional and commissioning factors.

*Table 3. Coding descriptors listed by group.*

|  |  |
| --- | --- |
| **Code** | **Description** |
| *Client Factors* | |
| Person Centred | Approach considers all client needs and all aspects of their lives whilst working with client as equal when planning, developing and monitoring intervention. |
| Complex Physical Health needs | Co-morbidities, postural deformities, musculoskeletal deformities, tonal abnormalities, respiratory complications, pain. |
| Mental Capacity | An individual’s ability to make decision about their care including best interests decisions and choice. |
| Participation | Interaction in activities, which enhance quality of life and integrate other systems including sensory and learning. |
| Environment | Impact of equipment on environment, other residences, social circumstance. |
| *Carer Factors* | |
| Carer Needs | Carer fitness, mental health, respite, functionality of equipment. |
| Knowledge and skills | Education, information sharing, training, product information. |
| Accessibility of services | Availability, contact, service awareness, negotiating health and social care. |
| Expert carer | Carer's knowledge and expertise on the client they work with. |
| *Professional Factors* | |
| Specialist Assessment | Assessment and review undertaken by a professional with experience and expertise in the given field. Specialist knowledge of available products. |
| Professional Values | Attitudinal and behavioural values demonstrated by professionals towards clients and carers. |
| Communication | Providing information, guidance, documentation to support intervention. |
| Advancing Practice | Use of technology to enhance service delivery and understanding development in products available. |
| *Commissioning Factors* | Service structure, funding allocation, staffing, access to specialist services. |

Interpretation of the themes extracted from the data, is discussed below under sub-sections using the coding descriptors outlined above. Adopting this structure allowed for summary of the participant’s views, any sub-group analysis and comparison with existing literature.

**3.1 Client Factors:**

Across all of the interviews conducted, client factors were discussed as primary enablers and barriers in the delivery of 24-hour postural management, with person centred care, participation and mental capacity the perceived roots of intervention success. Complex physical health needs and environment were also perceived as important client factors. The weight of these factors varied between paid and informal carers. Complex health needs were discussed extensively by parent carers, whereas, the environment was discussed at length by paid caregivers working in shared homes.

**3.1.1 Mental Capacity:**

On discussing all therapeutic activities included within the fictional programme each of the participants highlighted the need to prioritise the choice of the person they support over the action plan recommendations, regardless of level of learning disability. Although paid caregivers talked more explicitly about application of the Mental Capacity Act (MCA) (DoH, 2005), parents talked about the need to promote and enable choice. Ultimately all participants felt unable to deliver an intervention for the person they supported if they felt they would object to it, regardless of benefits promoted by clinicians.

*“She still has her own mind and there is a possibility that she wouldn’t want to do and then we wouldn’t.” Ben.*

The MCA (DoH, 2005) is rarely discussed within existing literature but this may be attributed to the predominant focus on children and application of the MCA (DoH, 2005) to people over the age of 16. However, as highlighted above, parents reiterate the need to consider an individual’s choice regardless of their cognition and ultimately their age. Within clinical practice there is likely to be a discrepancy between providing intervention in a person’s best interests, when they lack capacity, and fully understanding an individual’s perceived choice. This is supported by Dunn, Clare and Holland (2010) who evaluated application of the MCA (DoH, 2005) within care homes supporting adults with learning disabilities. They conducted 21 interviews with caregivers and found, despite the legal requirements, caregivers interpret decision making in a broad way involving their own feelings and attitudes. Adopting a “life like ours” approach (Dunn, Clare and Holland, 2010) caregivers project their own values on decision-making rather than objectively considering the best interests of the person. This would likely impact on delivery of professional recommendations without suitable caregiver education and guidance. It is pertinent to note that Dunn, Clare and Holland (2010) do not describe the situations in which caregivers adopt this approach so this may not include delivery of professional recommendations.

We must also consider the skills of clinicians, as well as caregivers, in evaluating mental capacity and making best interest decisions. Willner *et al*., (2011) conducted 40 interviews of health and social care professionals working with adults with learning disabilities who had, mostly, attended MCA (DoH, 2005) training. They found significant gaps in knowledge and inconsistent application of principles across three different situations. These situations did not include implementation of postural management guidance for adults with PMLD, however, it does highlight the need for clinicians to be aware of their own knowledge of the legislation as this may impact a client and their support network.

**3.1.2 Person-centred care:**

From the perspective of parents supporting adults with PMLD, discussing person-centred care provoked an emotional response. This was described as a factor affecting delivery of postural management and professional relationships overall. This theme arose repeatedly, however, was described by parents tending to refer back to historical events when asked about their experience of postural management.

*“We have had to walk out of several situations because we feel that professionals need to treat our daughter as a person and be respectful” Danielle.*

Similarly to themes relating to choice, person-centred care is not explicitly discussed within the existing literature. It could be considered, if person-centred care is driven by an individual’s values, needs and preferences (Health Education England, 2018) all client factors discussed could be deemed person-centred. However, within the interviews conducted this theme was reiterated multiple times as a standalone point with participants referencing the need for improvements in person-centred care and for professional’s to treat the people they support as individuals and as ‘a person’.

The need for improvement in person-centred care is supported by Dowling, Manthorpe and Cowley (2007). They reviewed practice and policy literature and found inadequate implementation of person-centred care across learning disability services in England. The reasons given include professional power imbalance, funding, lack of training and lack of experience. Any improvements in practice were not viewed as institutional initiatives but rather credited to individual professional enthusiasm. This study was written in 2007, since which a number of pivotal national papers have been published, which outline the extent of the health inequalities experienced by adults with learning disabilities and how person-centred care can avoid premature mortality (Mansell, 2010; Heslop et al. 2013). Possible changes in practice over time could account for the historical nature of the experiences shared by participants.

**3.1.3 Participation:**

The client themes discussed are underpinned by the need for collaboration of experience, knowledge and values between professional’s, caregivers and adults with PMLD. Designing postural management programmes to focus on participation reinforces the need for effective collaboration. Notably when discussing the standing frame element of the fictional programme presented, participants highlighted the need for prescription of this, more physical activity, to be given greater consideration. Guidance provided needs to include explicit instruction on why and when this activity should be undertaken with direction on how to integrate this into daily participation activities, rather than presented as a single intervention. Furthermore, standing frame use evoked a strong view regarding choice. Participants expressed that if standing frame use is not agreed with those receiving the support, implementation will be impacted and often terminated.

*“She was so much higher than everybody else. They were sat down or in their wheelchairs, and she’s tall anyway so then it made her a giant.” Alice, discussing experience of a standing frame.*

*“We need to think about this in a more well rounded way and this needs to be made clearer for staff and the focus needs to be changed.” Emma, discussing need to change focus to increase participation.*

The participants within this study are currently providing 24-hour postural management programmes provided by physiotherapists, as per the inclusion criteria. The Chartered Society of Physiotherapy defines physiotherapy as helping to *‘restore movement and function when someone is affected by injury, illness or disability’* (CSP, 2019). Overall, participants suggest that a focus on body structure and function is a barrier to delivery of 24-hour postural management. As suggested by Emma, the focus of intervention should be changed, instead enhancing participation and quality of participation within daily routine. This is supported by Goodwin *et al*. (2017) who, using semi-structured interviews, explored the views of children using standing frames. They similarly found that standing frames have the potential to impact both positively and negatively on a young person’s life, often with conflict between a) body structure and function and b) quality of life. Similarly to Alice, they described opportunities in which standing frames can promote participation but note during other, more physical group activities, these can be considered isolating.

Bray *et al*. (2017) also employed semi-structured interviews, to explore participation in children using wheelchairs as their primary form of mobility. Their study focused on the relationship between quality of life and wheelchair use. They highlighted that without the ability to move independently, children, are unable to have full control over their social interactions. Therefore, conclude that use of an appropriate wheelchair enhances participation. This study is not easily compared to the results from this study of adults with PMLD as it focuses on children and independent mobility with a wheelchair is not applicable for all adults with PMLD given the complexity of their disabilities. However, the study does reiterate the need for clinicians to consider when and how postural management equipment is used, which is consistent with the data in this study. It also highlights the need for equipment to be optimally suitable to support daily tasks, again echoing the theme of person-centred care emerging from this data set.

Remaining client factors, including the impact of complex physical health needs and the environment, were discussed at length but considered differently by paid and informal carers. Paid caregivers, more often, discussed the impact of the environment, including the impact on shared living arrangements, whilst informal caregivers prioritise complex physical health needs. This could be influenced by the settings in which they provide support or the emotional investment of supporting a child with complex physical health needs over many years. This is not necessarily representative of the existing literature within which paid carers highlight both complex physical health and the environment as potential barrier to 24-hour postural management (Hutton, 2008).

**3.1.4 Complex Physical health:**

*“I think if you have other health needs, the heat, especially if you have epilepsy or chest problems that it your pressing concerns.” Ben.*

It is widely recognised that adults with PMLD have complex health needs and are considered four times more likely to be admitted to hospital compared with the general population (Mencap, 2001), which will significantly affect the individual and their caregivers. Concerns regarding the relationship between intervention and health needs, as highlighted by Ben, was discussed regularly as caregivers try to limit the impact of co-morbidities on the person they support. Management of complex health needs is openly prioritised over the potential physical benefits of the intervention provided. Within this study, the impact of complex physical health needs was relevant to all aspects of the fictional programmes presented, however, deemed most pertinent when discussing the use of sleep systems. It was suggested that use of a sleep system may exacerbate existing health needs and despite acknowledging benefits of the intervention.

The general health of those supported, by both paid and informal caregivers, is a recurrent theme throughout existing literature; considered a potential barrier to the delivery of positioning programmes for children (Goldsmith, 2000; Humphreys, 2010; Hutton, 2008; Hutton and Coxon, 2010). Complexity of physical health needs is also thought to increase caregiver demands physically and emotionally (Hutton, 2008; Venkateswaran and Shevell, 2008). Despite this, paid caregivers within this study did not prioritise health needs to the same degree as informal carers. There are a number of factors, which could contribute to these variations, including commissioning contracting, more rigorous application of the MCA (DoH, 2005) and decisions made in compliance with best interests principles (DoH, 2005). Also, we should not underestimate the impact of managing complex health needs throughout childhood as a parent, rather than a paid caregiver.

Whiting (2014) used semi-structured interviews, involving 33 parents of families with children with disabilities, to explore the impact of having a child with disability and complex health needs on family life. No age restriction for the children were applied however sub-groups were used to group the parents including those whose children who have a long-term disability, life limiting illness and those with a technological dependence. This study found that pressures of time and fulfilling multiple roles have a significant impact on the family for all groups. These pressures are exacerbated by managing medication, implementing professional guidelines and using equipment to fulfil activities of daily living. It also highlighted conflict between some roles and caregivers are required to prioritise e.g. seizure management prioritised over meaningful occupation. Ben reiterates this within this study, prioritising seizure and respiratory management over postural management. Despite, again focusing on children, Whiting’s (2014) findings may hold relevance for parents supporting adults with PMLD. Multiple roles and pressures remain into adulthood and continue to emotionally impact parents.

**3.1.5 Environment:**

Environment was highlighted as both an enabler and barrier to postural management delivery. This was clearly reported by paid caregivers but did not emerge from informal caregiver sub-datasets. Consideration was given to both the adult with PMLD supported within a shared home environment and the needs of other residents they may share with. Primary consideration was given to the impact of introducing equipment into a shared environment.

*“This is a shared house so we then need to consider the impact that has on the other residents and will they tolerate those changes?” Charlie, discussing the standing frame.*

Maher *et al*. (2011) and Hutton (2008) describe environmental barriers, expressed by staff, impacting delivery of 24-hour postural management, within schools rather than shared homes. The challenges identified included availability and storage of equipment rather than the impact on other learners. Given that paid caregivers within this study are discussing an individual’s home environment it is unsurprising that the impact on others, cohabiting, would need to be a consideration. The ICF (WHO, 2001) supports clinicians to consider an individual’s environment within clinical decision-making and describes the environment as the physical, social and attitudinal environment in which a person lives. In addition, the ICF Checklist (WHO, 2003) does identify the need to consider relationships with others, however, it does not prompt assessment of the impact on others within the home. As highlighted by Charlie, if considered by caregivers a barrier to postural management, clinicians must also consider the impact on other residents when providing recommendations within a shared home.

The client factors enabling and acting as barriers to implementation of 24-hour postural management from the perspective of caregivers do not standalone. It is clear that these interact with each other e.g. choice could be affected by participation, which could in turn influence relationships with others in a shared environment. Therefore these themes should all be considered during clinical decision-making. Ultimately without placing the adult with PMLD at the centre of their care 24-hour postural management will be significantly confounded.

**3.2 Carer Factors**

Across each of the interviews carer factors, although considered important, were deemed secondary to the client factors discussed, as highlighted in the statements below from Charlie and Florence.

*“at the end of the day that is our job” Charlie.*

*“we all have the same interests - to make life better for our client” Florence.*

Given the reliance on caregiver’s to deliver 24-hour postural management programmes, factors affecting them have potential to significantly influence the interventions recommended, even if all client factors could be effectively integrated into decision-making. All participants described a wide variety of the enablers and barriers impacting them as caregiver’s. This ranged from personal needs, skillset, accessibility of services and the need to consider caregivers as an expert in the person they support.

**3.2.1 Understanding caregiver’s personal needs:**

Informal and paid caregivers discussed their own needs with different emphasis. Parents discuss emotional needs and the long-term impact of supporting an individual with PMLD, whereas, paid caregivers discuss the impact of carer fitness and internal values such as self-confidence.

*“I think, we have got so much else emotional stuff going we just go and don’t think "Oh I should be doing that".” Alice.*

*“There is staff fitness, (do we) have two fit members of staff.” Emma, discussing manual handling associated with therapeutic positioning.*

The emotional needs of caregiver’s are discussed from the perspective of both paid and informal carers within wider 24-hour postural management literature, however, this again focuses on those supporting children rather than adults (Hotham *et al*., 2017; Hutton, 2008; Whiting, 2014). Hutton (2008) highlights the emotional impact and anxieties experienced by carers supporting children with complex needs, whereas, Hotham *et al*. (2017) suggests the need for clinical training to address problems with confidence for paid and informal caregivers. Furthermore, Whiting (2014) not only details the emotional burden and impact on relationships when supporting a child with complex disabilities but also highlights the financial implications (Whiting, 2014). Although not explicitly discussed by the participants in this study, there are likely variations in funding streams for adults with PMLD, therefore, funding could present as a significant factor influencing any differences between barriers identified by informal and paid caregivers.

Carers UK (2004) report that 21% of caregivers, compared with 11% of non-caregivers, are considered to posses physical and/or mental poor health. This increases with the amount of care provided and those providing over 50 hours of care weekly are most at risk of deterioration in health. This does not account for any cumulative effect of caring for an individual for a prolonged period e.g. through childhood and into adulthood and so could not be estimated for the population of caregivers supporting adults with PMLD. This report (Carers UK, 2004), only considers the needs of informal carers. However, there are elements discussed within this report, such as risk of chronic musculoskeletal injury, which could equally be applied to paid caregivers therefore should be considered by clinicians when providing recommendations.

**3.2.2 Knowledge and skills:**

The importance of developing knowledge and skills, lead by the clinician, is agreed across all participants within this study. The importance of understanding the benefits and logistics, in addition to how to react when things do not go well, was discussed at length by paid and informal caregivers. This was most relevant when discussing aspects of the programmes considered most complex including standing frames, therapeutic positioning and sleep systems.

*“It is a whole staff team approach, training though needs to come from the professional.” Charlie, discussing responsibility of intervention delivery in contrast to training.*

Delivery of training packages to caregiver’s, to enhance delivery of 24-hour postural management, is well supported within existing literature focussing on children (Goldsmith, 2000; Humphreys, 2010; Humphrey’s and Pountney, 2006). It is suggested within existing literature, that tailored training packages should be delivered to caregivers to improve knowledge of what support is required and from whom specialist advice should be sought. Furthermore, Hotham *et al*. (2017) found that practical elements, especially experiencing postural management interventions, were deemed most effective training tool and report an improvement in knowledge, understanding and confidence following training. The need to develop skills and knowledge to ensure effective delivery of 24-hour postural management is not only applicable to caregivers. As documented by Page and Clayton (2016) and Castle, Soundy and Stubbs (2014) healthcare professionals also need to develop their skills and knowledge to assist and facilitate suitable access to services.

Although clearly an important factor affecting delivery of 24-hour postural management, there remains lack of guidance or clarity on what should be included within training. However, given the individual needs of the adult with PMLD and their caregivers, as highlighted within the themes derived, this seems acceptable. Clinician’s therefore need to develop their skills and expertise to understand factors most pertinent to those they are working with and design bespoke training tailored to their needs.

**3.2.3 Expert carer:**

*“Listening to what we, as carers, think might help. You know not just looking at what is right for the person we support.” Florence.*

In contrast to existing literature (Goldmsith, 2000), being considered an expert in the person they support was not solely discussed by parents. Paid caregivers similarly express the need to be respected as experts in the person they support. Understandably, this cannot be generalised across all paid caregivers considering some providers may experience high staff turnover and use of agency workers so experience may vary. However, this should remain a consideration by clinician’s when working in collaboration with all caregivers.

Sadler and McKevitt (2013) support the idea that informal caregivers are recognised as key providers of information, however, argue that to be considered expert caregivers they require specialist training from health professionals. In contrast the participant’s within this study and Goldsmith (2000), consider some caregivers expert solely given their extensive knowledge of the person they support. Arguably, as highlighted by Dunn, Clare and Holland (2010) caregivers may project their thoughts, feelings and values onto the individual they support influencing their perceived expertise. As concluded by Sadler and McKevitt (2013) clinician’s must, on balance, consider that caregivers have extremely useful knowledge and information to share whilst still benefiting from professionals imparting, discipline specific, knowledge and skills. It is pertinent to note that caregivers within this study, do identify the need to be considered an expert caregiver whilst also identifying the need to develop their knowledge and skills.

**3.2.4 Accessibility of services:**

Given the extensive support required by adults with PMLD, in all aspects of their lives, caregivers take responsibility for ensuring suitable and timely access to health and social care services (Mansell, 2010). However, the number of different services required at any given time can prove vast and varied whilst located in a number of different places. The experiences associated with ease of accessing services were reported as a barrier from the perspective of both paid and informal caregivers. No positive experiences from this perspective were reported.

*“There was a lag in the time and then she just never got it. There is a system of discharge, referral, allocation and then assessment. In the end we told them to go away.” Danielle.*

*“It makes you nervous about phoning up. You don’t know whether they will see her again, whether they will tell you that you need to do this or do that just to try and get her seen.” Florence.*

Whilst ‘accessing services’ is rarely reported in the literature, the more generic theme concerning the importance of communication is widely discussed within existing literature (Humphreys, 2010; Hutton, 2008; Castle, Soundy and Stubbs, 2014; Maher *et al.,* 2011). The focus of this literature tends to be on communication between professionals and how information is then imparted from professionals to the caregiver. Service accessibility and maintaining contact is not discussed within the existing literature, however, as highlighted by the participants within this study negative experiences impacts delivery of intervention whilst also impacting working relationships.

**3.3 Professional Factors:**

Professional factors ultimately underpin a number of the themes already discussed yet, the participants within this study, reported a number of new themes which focus primarily on the skills and values of the clinicians with whom they work.

**3.3.1 Specialist Assessment:**

Specialist assessment, clinical experience and knowledge was highlighted by all caregivers as an important factor influencing delivery of 24-hour postural management when asked to discuss their own experiences. An increased level of clinician knowledge and experience was thought to better inform caregivers, provide greater choice and it was deemed valuable for clinician’s to be able to work reflectively when making recommendations. There is also greater respect demonstrated by caregivers for clinician’s with increased knowledge and those deemed specialist.

*“I am reliant on professionals coming out and telling me what is available for the people we support.” Charlie, discussing the need for continued professional guidance.*

The need for specialist assessment, undertaken by a dedicated clinician, to facilitate effective application of the ICF (WHO, 2001) is discussed by Humphreys (2010) and Humphreys and Pountney (2006). They suggest that generic clinicians do not have the skills or expertise to provide postural management programmes and highlight this as a potential risk to clients. When considering the themes already identified within this study, this concept and integrating use of the ICF (WHO, 2001) facilitates person-centred care with a clear focus on client and their support network.

**3.3.2 Professional Values:**

Ali *et al*. (2012) conducted a systematic review and concluded that individuals with a learning disability and their caregivers remain the most stigmatised in society. The extent of this was found to impact on psychological well-being (Ali *et al*. 2012). Although this study explored stigma generally, rather than focussing on any specific associations with health intervention or health professionals. It does indicate the need for clinicians to consider their personal values and the impact that these will have on their care they deliver and their relationships they develop with caregivers. This seems especially pertinent to the experience shared by Danielle.

*“We went to him and he said “yes we will stick a metal plate in and it will stick out and might hurt. But this is what these people have.” So we just got up and walked out.” Danielle.*

When discussing professional values the most emotive responses from caregivers stemmed from experience outside of therapeutic intervention instead, as highlighted in the quote above, when Danielle was discussing surgical options for her child. Although 24-hour postural management can be used to reduce the need for surgery in some cases (Public Health England, 2018), this remains pertinent as adults with PMLD may continue to undergo surgery as part of their wider management programme (Mansell, 2010). There is limited research regarding clinician attitudes towards adults with PMLD, however, a study exploring General Practitioner’s (GP) attitudes to patients with learning disabilities (Gill, Sternfert- Kroese and Rose, 2002) reported that despite overall holding positive attitudes, GP’s were less positive about adapting their practice or behaviours. This study also suggested that the interface between GP and caregiver has an impact on the quality of care received by the client. This supports the statement made by Danielle, indicating that the way a professional addresses a concern, communicates with the carer and client influences outcomes and acts as a barrier to intervention.

**3.3.3 Communication:**

A number of communication forms are discussed within existing literature as influencing delivery of postural management including verbal communication (Humphreys, 2010; Maher *et al*., 2011), the development of written programmes (Maher *et al*., 2011) and effectiveness of clinical frameworks for communication between professionals (Hutton, 2008; Castle, Soundy and Stubbs, 2014). The theme of communication frequently emerged from numerous statements in all interviews with participants highlighting this as both a significant barrier and enabler to delivery of postural management. Paid caregivers more frequently highlighted the importance of the quality of communication provided by clinicians, whereas, informal caregivers tended towards highlighting the importance of communication between clinicians. This seemed especially pertinent when discussing the standing frame element of the fictional programme. Caregivers identified this as an area where changes could occur quickly and the need to make repeated referrals can act as a delay. To address this, as advised by Danielle below, caregivers highlight that having a single professional contact would be preferable and improve processes.

*“It would be nice to have a single therapist. But there is also a thing about not having referrals before there is a problem…Communication seems to have been lost unless it is through a letter or a referral.” Danielle*

This view is supported by Humphrey and Poultney (2006) who highlight the need for dedicated, specialist professionals working within a postural management service to reduce risk and increases effectiveness.

**3.3.4 Advancing Practice:**

Strongly linked with communication, participants highlighted the need for clinician’s to advance their use of technology to impart information and communicate with caregivers. Florence, provides an innovative idea in the quote below, underpinning this theme.

*“There may be something in providing video care plans as that belongs to the person and can show all aspects of the implementation.” Florence*

Advancing practice through communication was suggested to improve the quality of intervention by clearly demonstrating handling techniques and in turn adherence to postural management plans. This is not considered within existing literature, which may be due to the relative age of these studies. In real world practice, many clients and caregivers are used to using technology on a daily basis. Interestingly, Dallimore *et al*. (2017) used a randomised control trial to study the impact on patient education when using an iPad compared with a paper booklet. Arguably, the subject group within this study were patients post hip operation rather than a group of caregivers. The information presented on the iPad included videos and multimedia programmes imparting the same information as that presented in the paper leaflets. Despite both paper instruction and the iPad having positive outcomes, they concluded that the iPad improved recall of information. This finding, although with a very different subject group, reiterates the point raised by Florence within this study. This could help to influence practice and research in the future, however, there remain many other significant considerations in relation to use of iPads for communication. These include data protection, information storage and clinical record keeping which may need greater consideration when working with a adults who lack mental capacity associated with decision making (Mansell, 2010).

**3.4 Commissioning factors:**

The final group of factors reported by caregivers within this study as influencing delivery of 24-hour postural management relate to commissioning, which predominantly focussed on availability of funding and care-coordination.

Despite all participants highlighting funding and staffing as influential in delivery of 24-hour postural management this was not discussed in as much detail as initially anticipated. Florence, see quote below, highlighted that reduced staffing does act as a significant barrier to delivery of postural management, however, if caregiver’s understand the benefits of intervention they will continue to prioritise 24-hour postural management

*“There was a staffing issue as this needed two people but she got so much out of it that we would make the time and staff it regardless.” Florence.*

Commissioning matters extend beyond staffing issues and are more extensive when considering provision of equipment, wheelchairs and specialist services indicating the need for a care coordinator role to negotiate this. Danielle, below, identified this.

*“That person then follows things through…one thing I hate is chasing OT’s, physios and people. So maybe that key person could do that.” Danielle.*

Furthermore, CIPOLD (Heslop *et al.*, 2013) recommends that commissioners understand and value the need for expert services focussing on 24-hour postural management. Despite CIPOLD recommendations, there remain a number of acknowledged commissioning barriers affecting quality provision (Public Health England, 2018) including stringent eligibility criteria, access to equipment and lack of integration between organisations e.g. health and social care (Public Health England, 2018). Despite acknowledgement in the press and policy that commissioning can present as a barrier to quality provision, this is rarely discussed within existing 24-hour postural management literature. As highlighted previously this literature predominantly focuses on children for whom funding will vary compared with adult services. Interestingly, two of the participants within this study work within residential settings, thus experiencing different criteria, in respects to funding for equipment within a family home setting. Despite the potential for variation, this did not appear to change the attitudes of participants within this study and was not reported as a key-influencing factor in delivery of 24-hour postural management.

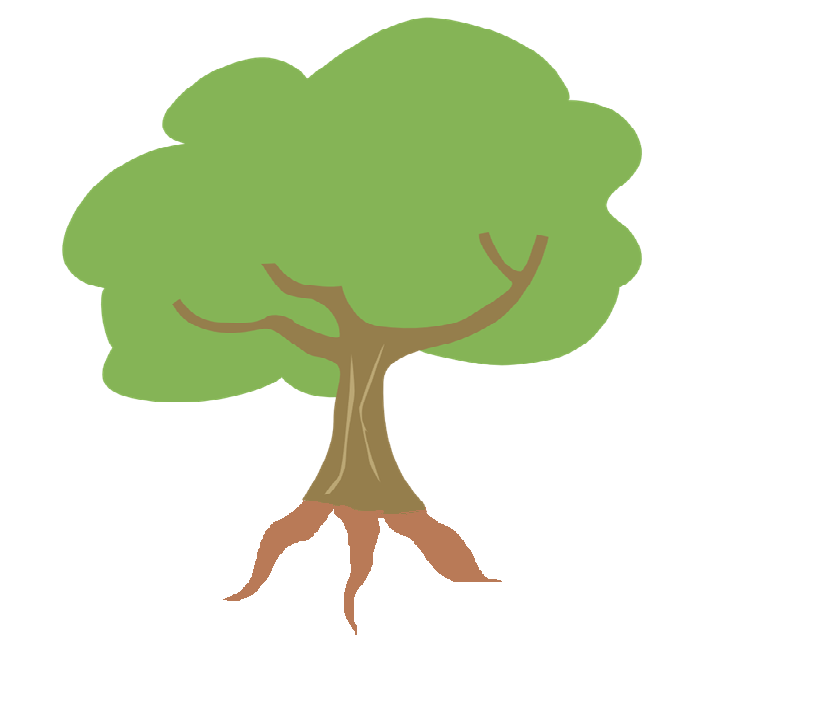
Making significant changes to commissioning is perhaps outside the remit of a caregiver or clinician. Despite this, there are a number of themes and factors discussed above that can be influenced by clinicians working in collaboration with caregivers to have positive outcomes for adults with PMLD. Potential clinical actions are outlined, with consideration of the arising themes, in the discussion below.

**4.0 Discussion:**

This study uncovered a variety of themes acting as both enablers and barriers to the delivery of 24-hour postural management. Some of these are discussed within existing literature, but a number remain exclusive to this study such as commissioning, professional values, mental capacity and choice. The findings of this study clearly portray the experiences of collaboration between caregivers and clinicians, whilst describing how these relationships influence the enablers and barrier outlined.

The barriers and enablers extracted from the emerging themes, can be categorised into four main groups client, carer, professional and commissioning factors. By examining the frequency of the statements made relative to themes, it is possible to prioritise the factors presented by caregivers. Client factors were discussed primarily, most frequently and with most emotion, whereas commissioning factors are considered less of a direct influencing factor. Upon synthesising themes according to the weighting, interaction and early interpretation, Figure 2 below uses a tree diagram to illustrate the barriers and enablers of delivery of postural management from the perspective of caregivers supporting adults with PMLD. This places key clients factors at the root and trunk of the tree, where addressing any barriers could yield more effective far-reaching positive impact. Carer, professional and commissioning factors are illustrated within the remaining branches as these could be considered the most accessible for professionals to utilise, impact or address. Although environment was considered a client factor within the results, this arguably affects the client, carer, professional and is influenced by commissioning, therefore, illustrates the environment around the body of the tree.

*Figure 2: Illustration of the barriers and enablers of delivery of 24- hour postural management.*



Professional

*Specialist Assessment*

*Communication*

*Values*

*Advancing Practice*

Commissioning

Carer

Client

*Care Coordination*

*Funding*

*Carer’s needs*

*Knowledge and skills*

*Expert carer*

*Accessibility*

*Mental Capacity*

*Person centred*

*Participation*

*Complex physical health*

Environment

The overall aim of this study was to explore the factors impacting on delivery of 24-hour postural management, from the perspective of caregivers supporting adults with PMLD. Understanding the relationships between complex physical health needs, lifestyle, support network, social environment and how this influences 24-hour postural management ensures a holistic approach (Hardy, 2004). Identifying potential enablers and barriers whilst finding means to enhance or utilise these could in turn reduce costs associated with secondary complications, ensure equipment and therapy input is used to its best effect and improve quality of life. Arguably many of the themes extracted from interviews with caregivers have significant overlap. A number of local clinical actions, as discussed below, could be potentially implemented, where clinically reasoned, to allow clinicians to modify their practice and develop caregiver engagement.

### **4.1 Potential action 1: A Dedicated Postural Management Physiotherapist**

Recruitment of a dedicated postural management physiotherapist is recognised within the existing paediatric literature as a means to enhance delivery of postural management (Humphrey and Poultney, 2006; Humphreys, 2010). Both, Humphreys (2010) and participants within this study, suggest that an experienced, specialist clinicians should have the skills and expertise to assess and impart knowledge to wider care networks (Humphreys, 2010). An increased level of knowledge and experience is thought to better inform caregivers, optimise communication, provide greater choice and was deemed of great value. Despite highlighting the need for specialism the existing literature does not identify how this specialist status is achieved. Should this be considerate of length of experience, variety of experience or academic training? Without guidance this could prove challenging for organisations to introduce and is likely to require a significant commitment in terms of training and development. Bennett and Grant (2004) discuss the need for physiotherapists to specialise in areas of clinical practice and identify that specialist’s should have (1) post-graduate qualifications within their area of interest, (2) a caseload primarily dedicated to their specialist area and (3) contributed towards teaching and training of others. Despite publication in 2004 and the likely progression of physiotherapy as a profession since this time, the key points made support many of the enablers identified by participants in this study including the need for caregiver training, clinician experience and knowledge.

Participants within this study also identified the benefits of a dedicated postural management physiotherapist to take a care-coordination role. Although this is not discussed at length within existing postural management literature, the importance of care-coordination is discussed as a means to ensure person-centred care (The King’s Fund, 2010). This publication collected evidence from ten leading voluntary, health and social care organisations before being independently reviewed and analysed (The King’s Fund, 2010). Following analysis, they advise that care-coordination is essential for individuals with long-term conditions and multiple morbidities to provide information, whilst listening to and communicating with clients and caregivers understanding their needs and concerns (The King’s Fund, 2010). This is a substantial role for any health professional, however, most importantly this role is described as a single, trusted point of contact for clients, carers and families. The introduction of a dedicated postural management physiotherapist therefore fulfils a number of the enablers and barrier identified by participants within this study.

### **4.2 Potential action 2: Integrated working across services**

The need to work collaboratively with caregivers and other professional groups was highlighted as an important enabler and barrier by participants within this study, considering the expert carer, service accessibility and communication. Similarly, the King’s Fund (2010) identifies a need for professionals to co-ordinate a multidisciplinary team to discuss clients’ needs and plan care. This is reiterated by the NICE guidelines for Cerebral Palsy in Adults (2019) which recommends not only that referral is made to multidisciplinary team if an individual deteriorates but also that reassessment by the multidisciplinary team may be needed at different points in their lives to ensure that their needs continue to be met. Arguably, this indicates the need for the continued involvement of other specialist professionals to ensure a holistic approach, however, the role of a dedicated physiotherapist remains pertinent to ensure coordination, integration and organisation of core-group meetings.

Whilst these NICE guidelines may not directly apply to all adults with PMLD, they remain pertinent when considering an individual’s complex health needs and how this affects delivery of 24-hour postural management. It is widely recognised that adults with PMLD are more likely to be admitted to hospital and live with a multitude of impairments affecting swallow, movement, vision and other co-morbidities including epilepsy (Mencap, 2001) which will significantly affect the individual and their caregivers (Whiting, 2014). Furthermore, Hotham *et al*. (2017) highlight the importance of providing clinical support alongside information in order to improve caregiver confidence. Therefore, providing the most appropriate clinical support and information regarding the complex health need of concern may improve caregiver confidence and therefore reduce barriers to delivery of postural management. For example, integrated working between the prescribing physiotherapist and a specialist epilepsy nurse when designing a 24-hour postural management programme, whilst delivering training and guidance in collaboration could improve caregiver confidence regarding complex health needs.

### **4.3 Potential action 3: Care Plan design**

The primary recommendation from participants in this study, regarding care plan design, was the need to advance practice with the suggestion made to use iPads or similar to capture guidance, which is supported by Dallimore *et al*. (2017). Delivery and communication of guidelines is widely discussed within existing literature with a strong focus on how information is provided in writing (Maher *et al*., 2011; Crawford and Curran, 2014). Furthermore, Public Health England (2018) recommends that simplified postural management guidelines should be shared with caregivers, whilst Houts *et al*. (2006) highlight that use of pictures improved adherence to health instruction. Participants within this study highlighted the importance of understanding the benefits and logistics, in addition to how to react when things do not go well. Any care-plans provided to caregivers, however presented, need to include this information with onward signposting provided to improve access to services.

Furthermore, a significant influencing factor in the delivery of 24-hour postural management was the ability of the clinician to adopt a participation rather than body structure focus. Effective application of the ICF (WHO, 2001) is therefore recommended to enhance identification of relationships between complex physical health needs, the support network, environment and participation. Understanding these relationships supports clinical decision-making limiting the impact of potential barriers and reducing risk (Hardy, 2004) however, this also needs to be reflected in the guidance shared to focus intervention on participation. Given the risk that caregivers may adopt a “life like ours” approach (Dunn, Clare and Holland, 2010) in which caregivers project their own values on decision making, care plans need to be agreed and clear in respect to individual responsibilities.

As discussed above, within this study, paid caregivers talked explicitly about application of the MCA (DoH, 2005) whereas, parents talked about the need to promote and enable choice. The result of not considering the choices of the client contributes to feeling unable to deliver intervention regardless of benefits promoted by clinicians. With this in mind, regardless of how a care-plan is presented, if the client is not engaged delivery of postural management will be impacted. To enable choice, clients and caregivers should be provided with all relevant information and this includes the opportunity to trial equipment ahead of decision-making. Therefore, all postural management services should have an appropriate assessment kit for trial and catalogue the variety of relevant companies and reps to offer reasonable choice. Furthermore, PMLD Link (2017) published essential service standards to support people with PMLD and advise that communication should be determined by the adult with PMLD with all individual means of expressing preferences, choices and decisions assessed to optimise the opportunity for an individual to express their views (PMLD Link, 2017). Humphrey’s (2010) also highlighted the need for clinicians to seek out the viewpoints of clients using alternate methods but within this study, participants also raise the need for communication to be supported by caregivers, adopting an expert carer role. Although in some cases communication may prove challenging, using alternative methods such as caregiver diaries to track a client’s responses during an equipment trial can help communicate an individual’s choice.

Ultimately when designing care-plans clinician’s need to consider how information is being communicated, e.g. using pictures, and how equipment is being used. Does it facilitate the client’s participation in activities they enjoy and how does it reflect their choices? Working in collaboration with caregivers and clients, using the ICF (WHO, 2001) to gather information and optimise communication may address a number of factors at the root of postural management delivery (Figure 2).

### **4.4 Potential action 4: Supervision**

Supervision should be considered from the perspective of clinician’s and caregivers. There is extensive evidence to support the emotional and physical impact of supporting an individual with complex physical needs (Hutton, 2008; Venkateswaran and Shevell, 2008; Whiting, 2014). This is reiterated by participants within this study who discussed their own emotional needs. Furthermore, given the necessity of delegation expected to caregivers, when providing 24-hour postural management programmes, it could be argued that physiotherapists need to implement a system of supervision. This will ensure the client and those delivering intervention are protected and risk is managed, as outlined in the CSP paper outlining responsibilities of delegation (CSP, 2007).

Supervision of physiotherapists is widely accepted as advantageous to clinicians allowing them to enhance their practice, accountability and promote their professional development (Clouder and Sellars, 2004). This is supported by the CSP (2017) who highlight that supervision should support and enhance practice for the benefit of clients whilst developing a clinician’s reflective skills. However, we must also consider, that despite the well documented emotional impact on caregivers outlined above, this does not consider the needs of clinician’s. Clinicians may have taken an active role with client and caregiver network, sometimes over many years, with a client group at risk of premature mortality (Mansell, 2010). Therefore, local systems for clinicians would likely benefit from review to ensure that this potential emotional impact is captured in supervision.

**4.5 Potential action 5: Training packages**

The importance of developing knowledge and skills, lead by the clinician, is agreed across all participants within this study and is widely agreed across existing literature (Goldsmith, 2000; Humphreys, 2010; Humphrey’s and Pountney, 2006). However, within these studies the subjects were parents whereas, adults with PMLD may live in homes with care commissioned from large providers. Hotham *et al*. (2017) delivered training to both paid caregivers and parents and reported an improvement in knowledge and understanding most notably when training included practical elements. Although this does not directly comment on the impact on delivery of postural management this did highlight an improvement in confidence following training.

Given the need to adopt a person centred approach, consideration of the caregivers needs and the need to deliver information that is relevant any training is likely to require bespoke training package. This could optimise the abilities of caregivers, improve esteem and develop the caregiver as an expert. This may need to be delivered jointly with other professionals to suitably target concerns regarding complex health needs and to ensure services are adopting a joined up approach. Ultimately, delivering bespoke training packages to all caregivers is more costly that generic group training. However, given the aim to reduce costs associated with secondary complications, acute hospital admissions and non-use of equipment, as with all action points discussed the investment is arguably worth it.

**4.6 Reflection:**

The key areas considered within the reflective diary, kept throughout this process, was the influence of the interviewer on the participants and the impact of any presumed themes that may arise from data collected. Furthermore, the questions asked and the style in which they were asked may have influenced the participant’s responses and therefore findings. As attitudes are formed in a social context (Hoey, 2014) my personal positive approach to subject matter may have influenced the participant’s responses. The methodology was chosen to limit bias and promote transparency.

Recruiting across the service, using the knowledge of physiotherapists outside of the research team, and approaching caregivers independently of their organisation reduced the impact of bias caused by familiarity of the interviewer and also reduced the influence of management structure on participant recruitment. Furthermore, using a pre-determined interview structure ensures that questions were asked consistently, limiting the influence on participant’s responses.

Limiting the impact of any anticipated themes on data analysis and theme extraction was perhaps the most challenging aspect of this study to manage. Transcribing verbatim using manual techniques rather than using any transcription programmes allowed familiarity with the data provided by participants. Using this method preserved meaning and reduced risk of data analysis misjudgements (Low, 2013) whilst ensuring that individual views remain embedded, maintaining transparency and rigour (Gale *et al.,* 2013). On reflection, increased familiarity with the data using manual techniques allowed for any preconceptions regarding themes to be addressed (Srivastava and Thompson, 2009).

**4.7 Limitations:**

Exploring the enablers and barriers experienced by caregivers is reflective of the service received locally, therefore, may not be generalised across services nationwide. However, clinicians may use the findings from this study, make connections with their own practice (Low, 2013). Arguably, this transferability can also be considered from the perspective of other postural management services for adults, without PMLD, with long-term neurological conditions. Then again, there are a number of considerations that would need to be made in terms of other adults with long-term neurological conditions including mental capacity and communication.

The knowledge and identification of participants was derived from the clinical practice of local physiotherapists’ enabling purposeful sampling. However, participation remained voluntary, therefore, the sample may not have been representative of the enablers and barriers experienced by all caregivers, with those having overly negative or positive experiences volunteering (Low, 2013). Similarly, during study design, it was anticipated that caregivers may wish to present an overtly positive view of their experience. This was thought to still prove valuable in exploring enablers but would still be considered a limitation. On reflection of the data collected, it was felt that overall caregivers presented a balanced view of enablers and barriers.

The interview structure used included a fictional postural management programme to understand how caregivers would react to a situation they can imagine themselves in. This programme was designed prior to recruitment and therefore the areas of postural management presented may or may not be familiar to participants. This could have influenced the responses provided.

**4.8 Future:**

Primarily, findings and actions will be shared locally during team meetings and professional away days with a view to enhance local practice. An event will also be coordinated locally and advertised via the same clinical physiotherapists involved in initial identification of potential participants. All interested parties, including caregivers, will be invited to this presentation of the results of the study, where lay summaries will be available. Any interested person (which upon analysis of the results may also include those who are now not identifiable as past participants) will be able to contact the researcher directly to request a copy of the lay summary.

This study has also been confirmed for presentation at the Physiotherapy UK conference providing opportunity to discuss and disseminate findings nationally. Subsequently, applications will be made to publish and further disseminate findings.

Indications for further research would include replication of this study in other areas of the country to compare caregiver’s experiences and allow comparison of findings, contributing to national guidance. Furthermore, reviewing caregiver experiences following any changes implemented in local practice would demonstrate the effectiveness of the actions presented within this study. Finally, repeating this study with other adult’s with long-term neurological conditions from the perspective of the adult rather than caregiver would give greater insight in delivery of postural management.

**5.0 Conclusion:**

The use of hypothetical scenarios within semi-structured interviews met the objectives providing an insight into the barriers and enablers of postural management delivery from the perspective of caregivers working with adults with PMLD. Participants demonstrated enthusiasm and willingness to discuss their experiences of 24-hour postural management, present and historical, giving a balanced view of both enablers and barriers allowing a clinical action plan to be developed.

Whilst some similarities between current literature focussing on the child population exist, this study has generated a number of new themes, which may be representative of changes over time and linked to understanding of the MCA (DoH, 2005) in adulthood. A number of clear enablers and barriers, identified by caregivers, can be grouped into four sets. The central themes, consistent across each interview, are considered client factors. These include choice, participation and physical health. The remaining themes are considered carer, professional and commissioning factors with a strong emphasis on the need for effective communication, specialist assessment and service accessibility.

Thematic analysis of participant’s accounts suggest the need to reduce focus on body, structure and function and increase focus on participation, when designing 24-hour postural management programmes. To best promote enablers and limit barriers, specialist assessment is advocated to consider the complex health needs and choice of clients whilst delivering bespoke training and documentation.

The overall aim of this study was to explore the factors impacting on delivery of 24-hour postural management, from the perspective of caregivers supporting adults with PMLD. Having identified potential enablers and barriers, whilst finding means to enhance or utilise these, can in turn reduce costs associated with secondary complications, ensure equipment and therapy input is used to its best effect. Ultimately improving quality of life for adults with PMLD and their caregivers.

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**Appendix 1: Interview Schedule**

Interview Schedule: Exploring delivery of 24 hour Postural Management

Version 2, Date: 06/06/2018, Project No: 242714

Thank you for taking part in my study exploring the enablers and barriers in supporting adults with Profound and Multiple Learning Disabilities (PMLD), when delivering a 24-hour postural management programme.  Have you had chance to read the information sheet? (If Yes or No, will talk through the information sheet to ensure that the participant is aware of all aspects of the project process). Ok, we will just take a short time to go through it anyway to make sure we are all clear about our aims and the process.

This interview is about exploring the enablers and barrier in delivering 24-hour postural management programmes. We will use an example of different prescribed postural management programmes to talk around different aspects of postural management and how this is delivered in current practice. We will discuss what works well and what could be improved. I expect the interview to last about 60 minutes. The interview discussion will be voice recorded using a Dictaphone and I will make notes about our body language during the interview. This will help me analyse the data more accurately.

I anticipate that some discussion may relate to professionals you have worked with and that also some of the issues we might discuss might be quite sensitive, so it’s really important that we all, me and you respect each others confidentiality. If you would like to raise any practice issues that may be related to the physiotherapist you work with, these will not be recorded for the purpose of the data collection. I am able to provide details for the Patient Advice and Liaison Service if you wish to make a formal complaint. If you are affecting by the topics discussed or become distressed during the interview, we will terminate discussion and provide relevant signposting to independent support. The nature of this signposting will be dependent on the nature of the distress and may include specialist caregiver forums or other health and social care services.

Also during this interview, if you raise any concerns regarding practice which may place anybody at risk or indicate bad practice, this will be escalated

through the safeguarding process therefore it is important for us all to be transparent throughout. Safeguarding is a framework in place to protect

vulnerable adults and support those who support them. It is important as it protects individuals from harm and ensures that they are receiving suitable, safe and appropriate care from the provider. To reiterate, this project has not been designed to test your performance or knowledge about 24-hour postural management programmes. It instead aims to explore the perceived enablers and barriers by discussing your experiences of 24-hour postural management.

Whatever you say will be recorded and allocated a pseudonym, this will not be available to anybody outside of this room and will be stored securely on in an encrypted file. I assure you, I will take great care in respecting your confidentiality at all times. When we talk about confidentiality we are talking about privacy in respects to personal information. When talking about clients you work with or clinicians you work with we will protect their names and identities. This may mean giving them fake names or referring to people as he/she so that we are able to identify them in any way. Other than your phone numbers for contacting if necessary in the future, I will not be storing any

personal information. The personal information (your name and number) will be stored securely in encrypted files. It will not be passed onto third parties and will be destroyed at the end of the study.

Your transcript will be anonymised by giving one of the pseudonyms Annie, Ben, Charlie, Daniel, Emma or Florence.  Quotes may be used within the final piece of writing however these will be allocated to one of the pseudonyms above.

All anonymised interview data will be stored securely throughout the project & consent forms will be stored by the University for 10 years and then destroyed. OK? Have you had time to read the information sheets that you previously received? Do you have any questions about the information sheets?

Can I ask you then to complete the consent form please?  Thank you.

* For those who no longer wish to complete the consent form: Ok, we are no longer able to proceed without your consent. Thank you for your time. Are you happy to give any feedback on what has changed your mind? This will help me to address this if it is unclear for other potential subjects.
* For those who complete the consent form: OK, I just want to start by understanding your experiences of delivering a 24-hour postural management programme until this point. Can you tell me about your experiences (pause for response)?

What you find currently works well and what you feel could be better?

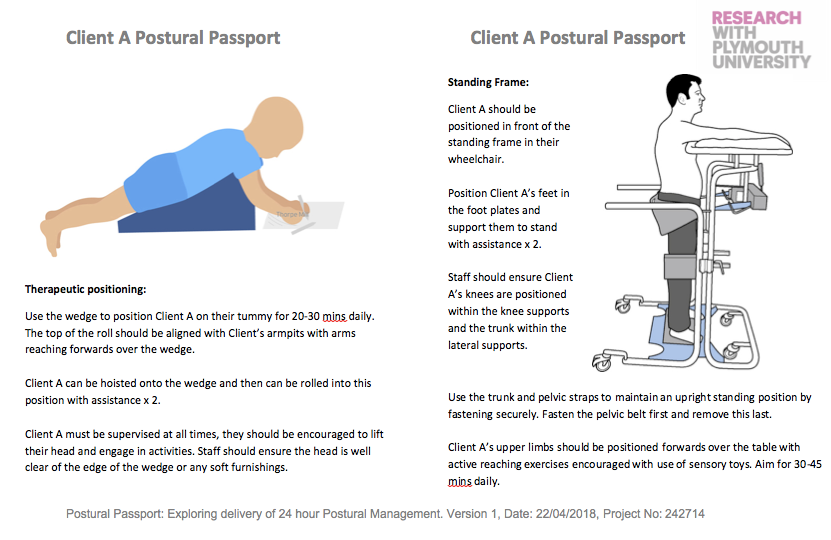
We’re going to look at the different 24 postural management programmes within Client A’s Postural Passport. We will then discuss these scenarios and how they would be delivered in practice.

* Ok so, what would be your initial feelings, personal feelings towards this programme given the information here?
* What do you feel your role is when delivering this programme and what are your expectations from the prescribing physiotherapist?
* What do you feel is necessary to make this programme work effectively?
* What do you feel would be helpful to make this programme work effectively?
* What do you think would be the potential barriers in implementing this programme effectively?
* Are there any factors which would prevent this programme from being delivered?

\*Drawing on what the participant says question why they think that and ask them to expand on what they are feeling, questioning why and what do they mean etc\*

Thanks for your time, I just want to reassure you that all the information will be stored securely & that anonymity will be respected at all times. Nobody outside this room will have access to the recordings. If you feel you need to discuss anything that has happened during this interview I can give you contact details for suitable support depending on the nature of these queries or concerns.

**Appendix 2: Fictitious Postural Management Programme**

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**Appendix 3: Participant Information Sheet**

Participant Information: Exploring delivery of 24 hour Postural Management

Version 4, Date: 28/06/2018, Project No: 242714

**Study Title**:“Exploring the barriers and enablers, from the perspective of caregivers, in implementing 24-hour postural management programmes within the home.”

**Purpose of study**:

The proposed study explores the enablers and barriers, from the perspective of caregivers supporting adults with Profound and Multiple Learning Disabilities, PMLD, in delivering a 24-hour postural management programme.The overall aim of this study is to improve joint working between caregivers and enhance delivery of 24-hour postural management services for adults with PMLD. This may ultimately result in changes to current practice and the service delivered. This study has been approved by an ethics committee.

**Why have I been contacted as a potential participant?:**

You have been recruited as you are a caregiver, paid or informal, with current experience of implementing a positioning programme of lying, sitting and/or standing for adults with PMLD over a 24-hour period. This study is voluntary so you can leave at any time before data analysis; there is no monetary incentive for either party.

**What will happen to me if I take part?**

If you decide to take part in this study you will be asked to participate in an interview and discuss a fictitious 24-hour postural management programme. This project has not been designed to test your performance or knowledge about 24-hour postural management programmes. It instead aims to explore the perceived enablers and barriers by discussing your experiences of 24-hour postural management.

Interviews will be no more than 60 minutes and semi structured in order to explore attitudes fully. This means that there will be some questions but mostly discussion. Questions will be used to direct discussion and to explore attitudes and feelings. These interviews will take place at an agreed location, locally, and voice recorded. You will not be interviewed with or at the same time as other study subjects to maintain your anonymity.

**What will happen to my data?**

The University of Plymouth is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Plymouth will keep identifiable information about you for 10 years.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find more information about how you’re your information will be used at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/).

All data will be treated with the maximum respect for your privacy. Data, collected using a Dictaphone, from your interview will be stored securely in and electronic format, this will only be available to the researcher. This data will be transcribed with original recordings deleted. Data will be allocated a pseudonym, within transcripts, to maintain anonymity and some anonymous quotes may be used within the project. Transcripts, along with consent forms, will be kept within secure electronic files at The University of Plymouth for 10 years. At your request the final project or your personal anonymised transcript can be reviewed however withdrawal will be allowed until the data analysis stage due to the impact on researcher and project. Anonymised quotes will be used in the thesis or subsequent papers.

The researcher will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from The University of Plymouth and regulatory organisations may look at research records to check the accuracy of the research study. The researcher will pass these details to The University of Plymouth along with the information collected from you. The only people in The University of Plymouth who will have access to information that identifies you will be people who need to contact you in extenuating circumstances such as illness, where the project needs to be stopped, or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The University of Plymouth will keep identifiable information about you from this study for 10 years following the study.

**Are there any disadvantages in taking part in this study?**

There are no disadvantages to taking part in this study but we may discuss issues that you may find sensitive, uncomfortable or potentially upsetting due to the complexities of clients with PMLD. This is a personal decision and there will be details available of accessible support services if you feel you require them.

These interviews will take place at an agreed local location, however, please note that no travel or parking expenses will be reimbursed.

**What happens if I raise concerns regarding the intervention or my experiences?**

If you raise any concerns regarding current practice you in your work place, you will be referred back to the prescribing physiotherapist to seek a review of the respective programme. Additionally, if significant concerns are raised indicating safeguarding concerns for caregiver or client, the usual local safeguarding process will be followed. Information regarding this process in available on the Devon County Council website. In both instances, you will be informed of the proposed actions, ensuring transparency.

If you are affected by the topics discussed or become distressed during the interview, we will terminate discussion and provide relevant signposting to independent support. The nature of this signposting will be

dependent on the nature of the distress and may include specialist caregiver forums or other health and social care services.

**What are the benefits?**

The benefits of taking part in this is to help us, as clinicians, understand how our current practice impacts on delivery of 24-hour postural management programmes within the home. From this, we hope to make changes to the service we deliver, ultimately making it more efficient, effective and accessible for adults with PMLD. This does not mean that you, as a potential subject, need to have a negative view. Positive experiences will equally help to influence potential change ensuring that this “best practice” underpins services across Devon.

**What happens when the trial stops?**

The information collected will form part of a MSc project and all results will

be kept confidential and available to subjects. All personal details will be destroyed on completion. Audio recordings will be securely destroyed after transcription and all data will be screened for any personally identifying data. If discovered this will be deleted from transcripts. Transcribed data, analysis and consent forms will be securely retained, by The University of Plymouth, in accordance with the General Data Protection Regulations for a period of 10 years before being securely destroyed. Transcribed data, analysis and consent forms will not be shared with any third party. The finished project will be read by third parties but there will be no personal information within the project, ensuring anonymity of participants. The aim is to publish this project in a peer reviewed journal and share it across the physiotherapy community to help improve practice in other areas.

**Do I have to take part?**

This project is voluntary and that withdrawal will not affect caregivers

interactions with the University of Plymouth (as sponsor) or local health and social care services.

As a paid caregiver, if you are interested in taking part in this study, it is advisable that this is discussed further with your employer to ensure they are also in support. A letter for potential participants to pass on to their

employers to give information to them, should they require it, is available. This outlines the purpose and aims of the study.

If you require any further information, please contact Laura Canning on 07792192880 or [laura.canning@nhs.net](mailto:laura.canning@nhs.net).

**Researcher:**

Laura Canning, Postural Management Specialist Physiotherapist working for Devon Partnership Trust.

My contact number is 07992191880.

This research project is being overseen by Dr Lisa Bunn at Plymouth University as it is part of a MSc project.

**Academic contact / contact for comments or complaints:**

Dr Lisa Bunn

Tel. 01752 588 882

Email: [lisa.bunn@plymouth.ac.uk](mailto:lisa.bunn@plymouth.ac.uk)

Plymouth University, Derriford Road, Plymouth PL6 8BH

Alternatively, you can contact Patient Advice and Liaison Service (**PALS**): 0800 0730741 - [dpn-tr.pals@nhs.net](file:///C:\Users\McCullarL\AppData\Local\Microsoft\Windows\Temporary%20Internet%20Files\Content.IE5\ZQYBOE7G\%22mailto:dp)

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**Appendix 4: Consent Form**

Research Consent form : Exploring delivery of 24 hour Postural Management

Version 1, Date: 22/04/2018, Project No: 242714

Researcher: Laura Canning – Specialist Postural Management Physiotherapist

Supervisor: Dr Lisa Bunn

**Title: “Exploring the barriers and enablers, from the perspective of caregivers, in implementing 24-hour postural management programmes within the home.”**

**Please initial the boxes**

I confirm that I have read and understood the information sheet describing the study.

I have received sufficient information about the study and have had opportunity to ask questions.

I understand that participation is voluntary and I may withdraw at any time before the data analysis begins.

I understand that all information will be treated as confidential and stored securely.

I understand that interviews will be recorded, data will be transcribed and checked by a third party but will be coded to respect anonymity and destroyed once the study is complete.

I confirm that quotations from the interview can be used in the final report and other publications if necessary. I understand that these will be used anonymously and I will be unidentifiable throughout.

I understand that any concerns arising throughout the interview will be escalated to the prescribing physiotherapist or, if necessary, through the safeguarding process.

I understand that my personal details will be stored duringthe study for contact purposes, my details will not be passed onto a third party and that this consent form, in addition to the original transcript, will be deleted after the completion of the study.

I agree to take part in this study.

**Subject Name (in block capitals):**

**Date:**

**Signature:**

**Witness Name (in block capitals):**

**Date:**

**Signature:**

**Researcher Name (in block capitals):**

**Date:**

**Signature:**

**Researcher contact details:**

Laura Canning, Postural Management Specialist Physiotherapist working for Devon Partnership Trust.

My contact number is 07992191880.

**Academic contact / contact for comments or complaints:**

Dr Lisa Bunn

Tel. 01752 588 882 Email: lisa.bunn@plymouth.ac.uk

Plymouth University, Derriford Road, Plymouth PL6 8BH

*(1 copy for researcher to retain, one for participant to retain)*

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**Appendix 5: Employer’s Letter**

Employer Information Letter: Exploring delivery of 24 hour Postural Management. Version 1, Date: 06/06/2018, Project No: 242714

**Study Title**:**“Exploring the barriers and enablers, from the perspective of caregivers, in implementing 24-hour postural management programmes within the home.”**

To whom it may concern,

A member of your staff team has registered their interest in participating in the research study above, this forms part of an MSc project. The proposed study uses 60-minute interviews to explore the enablers and barriers, from the perspective of caregivers supporting adults with Profound and Multiple Learning Disabilities, PMLD, in delivering a 24-hour postural management programme.The overall aim of this study is to improve joint working between caregivers and enhance delivery of 24-hour postural management services for adults with PMLD. This may ultimately result in changes to current practice and the service delivered. This study has been approved by an ethics committee.

This project has not been designed to test performance or knowledge about 24-hour postural management programmes. Nor has it been designed to gain information regarding individual organisations. It instead aims to explore the perceived enablers and barriers by discussing experiences of 24-hour postural management.

This study is voluntary so participants can leave at any time before data analysis; there is no monetary incentive for either party. Interviews will take place at an agreed location, locally, and will be voice recorded. Participants will not be interviewed with, or at the same time, as other study subjects to maintain anonymity. All data will be treated with the maximum respect for the participant’s privacy in corroboration with the General Data Protections Regulations, 2018.

If any concerns are raised regarding current practice, referral will be made back to the prescribing physiotherapist to seek a review of the respective programme. Additionally, if significant concerns are raised indicating safeguarding concerns for caregiver or client, the usual local safeguarding process will be followed. Information regarding this process in available on the Devon County Council website. In both instances, participants will be informed of the proposed actions, ensuring transparency.

The benefits of taking part in this is to help us, as clinicians, understand how our current practice impacts on delivery of 24-hour postural management programmes within the home. From this, we hope to make changes to the service we deliver, ultimately making it more efficient, effective and accessible for adults with PMLD. This does not mean that participants need to have a negative view. Positive experiences will equally help to influence potential change ensuring that this “best practice” underpins services across Devon.

If you require any further information, please contact Laura Canning on 07792192880 or [laura.canning@nhs.net](mailto:laura.canning@nhs.net).

Yours faithfully,

Laura Canning

**Researcher:**

Laura Canning, Postural Management Specialist Physiotherapist working for Devon Partnership Trust.

My contact number is 07992191880.

This research project is being overseen by Dr Lisa Bunn at Plymouth University as it is part of a MSc project.

**Academic contact / contact for comments or complaints:**

Dr Lisa Bunn

Tel. 01752 588 882

Email: [lisa.bunn@plymouth.ac.uk](mailto:lisa.bunn@plymouth.ac.uk)

Plymouth University, Derriford Road, Plymouth PL6 8BH

Alternatively, you can contact Patient Advice and Liaison Service (**PALS**): 0800 0730741 - [dpn-tr.pals@nhs.net](file:///C:\Users\McCullarL\AppData\Local\Microsoft\Windows\Temporary%20Internet%20Files\Content.Outlook\DBIV4CW1\%22mailto:dp)

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**Appendix 6: Mitigating Risk**

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| --- | --- |
| Risks | Mitigating Actions |
| Slow recruitment | * Regular discussion with colleagues to ensure all suitable subjects are recruited and any reported barriers. * Address any reported barriers. * Time allowed for recruitment – see Appendix. * Recruitment at caregiver level rather than “top down” approach. |
| Suitability of interview locations | * Choice of locations given to subjects. * Designated meeting rooms used away from busy environments. * Facilities booked in advance. |
| Poor quality data collection | * Pilot study undertaken. * Field notes gathered to support transcripts. * Systematic analysis of data using matrix. |
| Equipment breakdown | * “Back up” systems available. * Practice use of equipment. |
| Time delay due to IRAS process | * Time built into this process to support this. * Use of ADV715 project to support research design. |