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Experiences of patients and healthcare workers in the NHS pre- and post- Covid-19

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Master of Philosophy (MPhil)
June 2021

Keele University

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Abstract

This project assesses the benefit that qualitative investigation of experience brings to healthcare research. It does this through:

Phase One - Understanding the factors affecting AFO compliance in children with CP
People with cerebral palsy (CP) often use ankle-foot orthoses (AFOs) to support walking. Some literature suggests that adolescents with CP have low compliance rates (Wingstrand et al., 2014) but little research investigates the experiences of the patient in regard to AFO compliance or explores factors which influence their willingness to wear them. This project developed methodology to investigate AFO compliance in young adults with CP by assessing compliance levels, the biomechanical benefit of the AFO, and interviewing the user about their experiences of the device. A focus group was designed to explore peers' perceptions of AFOs for context and insight.

Phase Two - Investigating the experiences of healthcare staff during the Covid-19 pandemic
Covid-19 has significantly affected the world. While the physical impact of the virus is a research priority, the social and psychological effects also require investigation. One of the social impacts which occurred due to the pandemic is the development of boundaries in the workplace. This study investigated the impact of context and the social, psychological, and cultural mechanisms which caused the development of boundaries between staff in an NHS Trust. Diary entries were collected over three months to investigate the experiences of healthcare staff during the early months of the pandemic. In total, 13 participants submitted 97 diary entries. Two interviews were also conducted to gain contextual understanding. Data were analysed thematically and identified four themes, these themes highlighted the development of boundaries within the hospital. From this, it was possible to identify the mechanisms which caused them to emerge.

These phases highlight the benefits that exploring individual experience can bring to healthcare research and organisational management.

Acknowledgements

I would like to thank my supervisor, Caroline, and friend, Mihaela, for the guidance, support, and the wonderful conversations that took place throughout the project. The pandemic looked to be a period of stress and uncertainty for me as well as the participants I worked with in this study, but their knowledge, experience, and kindness has made this year a wonderful experience.
Thank you too to the Orthopaedic Institute for funding this study and providing the opportunity for me to carry out such interesting research.

This study would not have been possible without study participants who put aside time during a pandemic to write diary entries about their experiences. I am very grateful for their enthusiasm and willingness to engage with the project and the wonderful contributions they made in what was a very stressful period. I really appreciate the wonderful people in the hospital who were so supportive during a very stressful period, particularly Kerry and Claire who provided lots of support and advice while setting up the studies.

Finally, I need to acknowledge the work that my dedicated 'research cat' has done to support me while I've worked on this study. There has not been a day that he has not carefully sat on my notebooks, papers, or laptop to impart his wisdom. Thank you(?), Ffin.

Image i: 'Research cat' 'helping' (Own photo, 2020)

Abbreviations

AFO	Ankle-foot orthosis
FMHS REC	(Keele University) Faculty of Medicine and Health Sciences Research Ethics Committee
IRAS	Integrated research application system
MWL	Mixed work locations
RH	Reduced hours
WFH	Work from home
WOS	Work on site

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Chapter One: Introduction to the project

1.1 Introduction

Currently many healthcare studies, particularly those regarding the efficacy of medical treatments, rely on quantitative data gathered from large numbers of participants which assess the efficacy of the treatment in supporting the patient with their condition and note any limitations or side effects; compliance is generally assessed in a percentage of patient usage compared with prescribed or recommended usage. Relatively little attention is given to the experience of the user and the impact that the treatment has on their lives despite this being likely to impact on the extent that they engage with medical advice. Medical treatment does not exist in a purely quantitative state for the user, it interacts with their life: it affects how they feel or behave, or what activities they can participate in, side effects can outweigh the potential gain; in some cases the medical intervention can be perceived by their peers, it interacts with their clothes and activities and has a symbolic and aesthetic presence beyond its medical capacity. Similarly, in management research, the working environment and any changes implemented within the organisation do not exist in isolation from employees' personal lives. Things which happen at work affect individuals during their working hours but can also significantly impact on their private lives and have wider social and psychological implications, stress and burnout being just one example.

This aspect, the social and psychological impact that medical treatment or organisational change has on people's lives beyond the intended impact, is rarely investigated. Where it is, it is more often assessed with surveys, but many qualitative methods, like interviews or creative ethnographic methods, offer a way to gain valuable insight into a subject. They explore phenomena in a more holistic way and provide a means to allow participants an open opportunity to introduce or expand on topics which they think are relevant to shape their responses and produce rich data which can provide insight beyond the initial thoughts of the researcher – something which is harder to obtain through many quantitative, or survey based methods. This study will look at the data that can be obtained using these qualitative research methods in a healthcare setting, looking at both patients and staff, to see if the data collected can offer insight into experiences which can be used to better support staff and patients in the future.

1.2 Scope and boundaries of the investigation

Due to the impact of the Covid-19 pandemic on research and the limitations it imposed on data collection, this thesis will be constructed in two parts. Part one will investigate the experiences and perceptions of AFO users with CP to investigate the users' experiences and opinions of their device and see if there are any factors which are influencing their compliance levels. Only the supporting research and methodologies are featured in this thesis, however, due to Covid-19 restricting access to participants. Part two will explore the experiences of staff in an NHS Trust during the pandemic, looking at how they were affected personally by the virus, and how the organisational changes which occurred in the early months affected the staff and introduced boundaries between social groups within the workforce.

This thesis aims to determine the value that qualitative investigations can bring to healthcare environments. It does this by investigating the experiences of patients and staff, and looks to see whether the data which is produced can offer insight into the behaviours of the individuals, and whether that insight can be useful when developing future practice for patient treatment, or organisational changes to support staff, particularly in cases of crisis. It is hoped that the investigation of experiences will bring a wider understanding of the situations that staff and patients face in their lives which can be used when evaluating practice in the future

1.3 Structure of the thesis

The thesis is structured as follows:

Chapter one introduces the project, briefly exploring qualitative research, before introducing the rationale for the project, the two key studies, and the aims of the investigations.

Part one refers to the initial project investigating the factors which affect the rates of compliance in children with CP supplied with AFOs.

Chapter two introduces the subject of patient compliance with ankle-foot orthoses (AFO) wearing and situates it within the literature. It provides background knowledge on cerebral palsy and AFOs and discusses compliance and methods of monitoring usage.

Chapter three is made up of two literature reviews which investigate the current literature surrounding AFO compliance, and factors which influence patient compliance, particularly surrounding young people using AFOs. These reviews provided valuable context for the investigator and identified some factors which are likely to affect AFO compliance in young people.

Chapter four lays out the methodology for the studies proposed to investigate AFO compliance including technical information and the proposed materials and protocols. Due to the Covid-19 pandemic, however, none of these methods of data collection were acted upon.

Chapter five discusses a pilot study which was carried out to assess the suitability of the Orthotimer sensor for the study, including a brief discussion about the results.

Chapter six details the onset of Covid-19 in the UK and describes the reasons for the development and transition to the second study in the project.

Chapter seven introduces the supporting literature for the exploration of the experiences of healthcare workers during the onset of Covid-19 and pursuing lockdown period. It discusses Covid-19 as a wicked problem, the liminal position it placed the hospital in, and how those factors were likely to influence healthcare workers, also briefly exploring social boundaries within the workplace.

Chapter eight describes the methodology involved with exploring the experiences of NHS staff through the Covid-19 pandemic.

Chapter nine analyses the diaries collected from the health care workers. Chapter ten then goes on to discuss these findings in relation to the literature. Establishing a model for the development and perpetuation of social and symbolic boundaries within the Trust. Conclusions, limitations associated with this study, and recommendations for future work are also presented here.

Chapter eleven provides a summative discussion of all elements from this study, assessing the use of qualitative methods to conduct research into patients and staff in healthcare settings.

1.4 Ethical approval

Ethical approval was granted for all elements of this study.

Part one: Approval for the case studies: 3D movement analysis, compliance, and interviews, were all sought from the Integrated Research Application System (IRAS) (Application reference: 265723, Appendix 1). Approval for the school focus groups was granted by Keele University Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS REC) (Application reference: MH-190066, Appendix 2). All children and their parents gave written assent/consent before any participation took place.

Part two: the study was initiated as a management exercise within the participating hospital. Favourable ethical approval for use of the exercise as research and for publication of the findings was granted for prior to analysis for this study (Application reference: 286648, Appendix 11). All participants gave written consent for their data to be used for research beyond the management exercise prior to participating.

Additional information detailing the ethics for each section will be included in the method sections (Chapters four and eight).

1.5 A note on the use of the term ‘compliance’ in this thesis:

Across the first half of this thesis the term ‘compliance’ is used to refer to patients’ willingness to engage with the directions of a medical professional, particularly regarding the use of medical devices or orthoses. Since writing these chapters, further reading regarding the social connotations and significance of semantics used in relation to healthcare have suggested that ‘adherence’ is a more appropriate term to use in this situation. However, due to the time restrictions on the project, the language has not been amended within the thesis.

Wider reading of Disability Studies papers, greater familiarisation with the social model of disability, and discussion with more experienced researchers and clinicians provided a better understanding of the importance of person-centred care and the semantics of healthcare. A key element of this revolves around the use of person-centred language over deficit-based language. Use of person-centred language emphasises the person rather than the patient, it places the individual - as someone who has to choose to engage with and will have their lives affected by medical recommendations - at the centre of the medical approach rather than focusing on their medical condition as something that needs to be ‘cured’. By focusing on patients as individuals, it encourages healthcare professionals to recognise their autonomy and to support them with their unique needs as they live with their condition, rather than trying to meet biomedical norms which may not be relevant to their situation.

Language is an important element when discussing these distinctions and can be used to support and empower patients or can form a barrier between clinician and the individual they’re trying to support. While ‘compliance’ can be used to describe the extent that people engage with the recommendations of their clinicians, it is commonly accepted that ‘adherence’ is a more appropriate, person-centred term to use when describing this situation. ‘Adherence’ recognises the knowledge that patients have about their own situation and the relevance of treatment options within the context of their circumstances, and reinforces the autonomy that patients have towards their own care instead of placing them as passive receivers of treatment from their care team.

This study strove to recognise the complexities of young people’s adherence to medical advice regarding the usage of AFOs, with a particular interest in the wider interactions of AFOs with young people’s lifestyles and other personal factors which were likely to impact usage. Although the project planned to engage a person-centred approach to identifying factors which may affect the usage of medical devices, the use of ‘compliance’ was based on a biomedical-centred understanding of the situation. Had further time been available for the project, this would have been adjusted to better reflect the values of the study.

Part One: Understanding the factors affecting compliance in children with CP supplied with AFOs (Pre-Covid-19)

Chapter Two: Experiences and perceptions of AFOs

2.1 Introduction

Cerebral palsy (CP) is a lifelong condition which stems from damage to the parts of brain responsible for balance, movement, and posture either before birth or in the first couple of years of life (Krägeloh-Mann & Cans, 2009; Eunson, 2012; Novak et al., 2012). It is an overarching term for a range of disorders which mostly affect physical attributes linked to posture and movement, though these symptoms vary between individuals (Rosenbaum et al., 2007). Approximately 1 in 400 children are born with CP in Europe (Cans, 2000; Johnson, 2002) and whilst there are no singular causes of the condition (McIntyre et al., 2011), there are a number of factors which have been linked to increased risk (Odding, Roebroeck, & Stam, 2006; McIntyre et al., 2011; Tollånes et al., 2014).

The widely accepted definition for CP was devised by Rosenbaum and colleagues (2007) and states that CP is:

> "*a group of permanent disorders of development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing foetal/infant brain*"

The condition is heterogeneous, and its presentation varies in symptoms and intensity across affected individuals. While movement and posture are the dominant disorders linked with CP, patients often also exhibit varying degrees of difficulty with coordination, cognitive abilities, communication, vision, and hearing (Rosenbaum et al., 2007) which can also impact on developmental milestones (Rosenbaum et al., 2007; Eunson, 2012; Jankowska et al., 2015). CP is a lifelong condition and though the initial brain damage is non-progressive, the symptoms may change and increase in intensity as the patient ages (Haak et al., 2009). Due to this, CP patients continue to receive a range of therapies throughout their life (Jankowska et al., 2015).

While CP can cause impairments to an individual's lifestyle, the heterogeneity of the condition means that not all patients are acutely disabled. Although some people with CP do exhibit debilitating symptoms, others require little to no additional support in their daily lives (NIH, 2019). Roughly half of the population of individuals with CP are reported to have a quality of life similar to their able-bodied peers (Majnemer et al., 2007), and a great number are able to attend mainstream school and workplaces, and live relatively unimpaired lifestyles (Laws & Kelly, 2005; NIH, 2019).

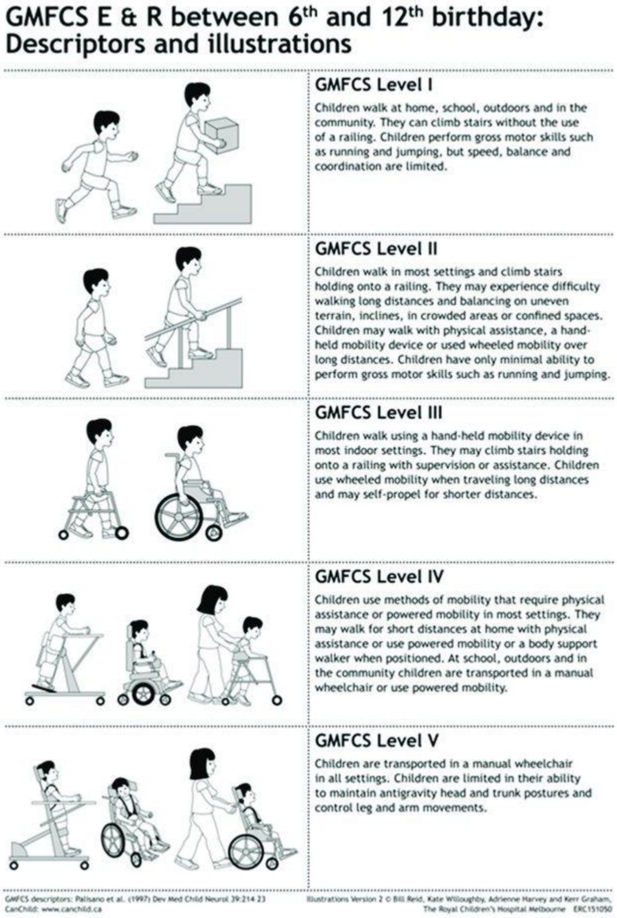
2.2 Classification systems

There are three main ways to classify CP. These systems categorise individuals with CP based on: the distribution of the impairments across the body, their motor impairment, and their motor skills (Becher, 2002; Rethlefsen et al., 2010).

Classification according to distribution of the condition across the body focuses on which limbs are affected: Quadriplegia describes people with CP who are affected in all of their limbs, both arms and both legs and sometimes other symptoms in the face or trunk; whereas people with biplegia have only two limbs that are affected by the condition. People with biplegia can either have diplegia, where both legs are affected, though arms may also be affected to a lesser degree; or hemiplegia where one side of the body is affected (one arm and one leg on the same side).

Motor impairment is classified into four groups according to the type of impairment observed within the body: spastic, dyskinetic, ataxic, and mixed. While each of these categories occurs independently, they can also occur in combination with each other (Cans et al., 2007; Krägeloh-Mann & Cans, 2009; McIntyre et al., 2011). Spastic CP is one of the most common types of CP, affecting 77.4% of people with CP (CDC, 2019). Spasticity describes the over contraction of muscles, and this can cause muscle tightness and stiffness which can make it difficult for patients to control the limbs and can cause pain, affecting the walking and arm movements of people with CP. Over time muscle spasticity can also contribute to greater symptoms of reduced muscle length or joint dislocation and affect the person’s posture. Dyskinetic CP affects approximately 12% of affected individuals (Becher, 2002). People with this condition exhibit involuntary muscle contractions and movements and this can cause pain and complicate carrying out controlled, elective movement such as walking, but can also affect movements like speaking or swallowing. Ataxic cerebral palsy affects about 4% of people with CP, affecting their balance and coordination and also their proprioception. This can make it more difficult for individuals to walk or carry out limb movements because it causes the motion to be shaky and jolted, though most children do learn to walk in time with or without assistive devices to support them (Becher, 2002).

The general motor skills of people with CP are assessed using the Gross Motor Function Classification System - Expanded & Revised (GMFSCS or GMFSCS-E&R) (Palisano et al., 1997) which is made up of five levels, see image 1 below. Each level is made up of a description of ability at a particular age group. Motor skills range from level I, where children are able to walk around their home and outside without assistance including running, jumping, and climbing stairs unaided but with some limitations; to level V, where children rely entirely on externally driven means of transportation like wheelchairs for all movement, and have limited ability to control their limbs, head, or trunk (Palisano et al., 1997). The GMFSCS assessment is used for patients from infancy through to 18, though typically children do not shift between levels after two years (Gorter et al., 2009). The results of a GMFSCS assessment allow medical professionals to identify the abilities and needs of the people with CP which gives them a basis to consider treatment options and support for the individual, and predict how their symptoms of CP will develop in the future (Palisano et al., 1997).



GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

GMFCS Level I

Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.

GMFCS Level II

Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.

GMFCS Level III

Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.

GMFCS Level IV

Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.

GMFCS Level V

Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,
The Royal Children's Hospital Melbourne ERC151050

Image 1: GMFCS Descriptors and illustrations (Palisano et al., 2007)

2.3 Treatment

Although there is no way to cure CP, there are a number of therapies and treatments which can be employed to help treat the symptoms which develop as a result of the condition. The diversity of symptoms means that there are a number of therapies which may be useful for people with the condition, and most patients will be given a combination of treatments at a time. These treatments may include: physiotherapy, occupational therapy, hydrotherapy, speech therapy, assistive devices, surgery, botulinum toxin injections, and medication (NIH, 2019). Many people with CP are also given assistive devices to support them in their day to day activities including: computers to assist with school work or communication problems, or walking devices, including orthotic devices, to help support mobility (NIH, 2019). Assistive devices can make enormous impacts on the lifestyle and allow patients to increase their independence and ability to engage with the wider world around them and are essential to many patients' lives (Osam et al., 2019).

2.4 CP and walking

Walking and movement is typically affected in all people with CP. However, approximately 50-80% of children with CP are able to walk to some degree (Armand et al., 2016), and many children with CP GMFSCS levels I or II are able to take part in sport with able-bodied children (Clutterbuck, Auld, & Johnston, 2019). Most people with CP will display a pathological gait, with kinetics and kinematics that differ to those of a normal gait. Due to the nature of CP, the extent of the deviation varies between individuals, but it is suggested that it can cause children to spend 2-3 times the amount of energy to walk as able-bodied individuals (Brehm et al., 2008). One of the physical outcomes of this increased energy expenditure is increased fatigue and tiredness to the child (Brehm et al., 2008) which can make it more difficult for them to carry out daily activities. By introducing interventions that positively influence the kinetics and kinematics of gait, medical professionals can improve the walking ability of children and reduce the metabolic cost, which can have a significant impact on their lives. There are a number of different treatment options available to support the locomotion of children and adults with CP: physiotherapy, botulinum toxin injections, surgery and a range of different devices which assist walking including rolling walkers, crutches, and splints/braces. These are not necessarily exclusive, and a patient will often receive multiple treatments in combination to achieve the best results (Eddison, 2018). Treatments may also be introduced or altered as the patient ages to adapt to the range of changing symptoms and to try and help them achieve as much mobility and independence as possible.

2.5 AFOs

Ankle-foot orthoses (AFOs), sometimes referred to as splints or braces, are one of the most commonly prescribed orthoses for children with CP (Morris et al., 2011; Wingstrand et al., 2014). AFOs come in many forms but generally consist of a rigid structure, commonly made of polypropylene or carbon fibre, which fits around the leg from just below the knee to the toes in an L-shaped support. AFOs are adapted specifically for the individual they are prescribed for, their biomechanical requirements, and the scenarios in which the orthosis is likely to be used. The properties of an AFO can be established and adjusted by modifications to the design, the material used, and the stiffness of the material, to better enable it to support the user (Singerman, Hoy, & Mansour, 1999).

AFOs are worn as part of daily activity and support patients as they walk and carry out activities (Schwarze et al., 2019), normalising their gait patterns (Aboutorabi et al., 2017). The structure acts in a number of ways: protecting the lower limb from harm, correcting deformity, and helping to improve the range of motion at the ankle and knee joints, which in turn works to improve the posture and walking efficiency of the user, and provides stability and support to the leg (Fess, 2002; Wingstrand et al., 2014; Totah, 2019). Practically, AFOs are designed to provide a means for children to walk more comfortably and stably over longer distances. In supporting regular movement so, they provide some protection against the deterioration of walking abilities (Day et al., 2007), and support the user as they carry out their daily activities (Nooijen et al., 2014), which also potentially improves independence, quality of life, and patient wellbeing.

The literature is somewhat varied regarding the efficacy of AFOs with a number of papers stating conflicting findings, and varied results according to the type of AFO or classification of CP (Lintaf et al., 2018). However, a systematic review and meta-analysis of the existing literature reported that there was a strong suggestion that AFOs make improvements to the gait of children with CP to a greater or lesser degree, with strong evidence to support some positive changes in the biomechanical aspects of gait, and improvement to the gross motor function of the user. Most notable improvements for users were an increase in stride length and a smaller increase to the speed at which the children walked (Lintaf et al., 2018). A common criticism in the literature, however, is that studies which have investigated efficacy of AFOs have noted the inconsistency across journal articles reporting the properties of the AFO, e.g. material, stiffness, or thickness (Eddison et al., 2017; Lintaf et al., 2018). Given that the AFO properties impact on the effect that the device can have (Singerman, Hoy & Mansour, 1999), this could lead to misleading results regarding the AFO's efficacy.

This project will focus on solid or fixed ankle AFOs, see image 1, which are made up of a single piece structure that doesn't allow any flexion or motion of the foot or ankle. The fixed AFO supports the ankle and foot in a single position, usually at 90^{o}, from the lower leg and restricts movement in the sagittal, coronal, and transverse planes which can help to counter any problematic positioning of the foot or leg. In the patients who use AFOs, this can often provide a more stable base for walking in children with CP (Fess, 2002).

Image 2 - An example of a fixed, polypropylene AFO with pattern. (Lakeland Orthotics, 2020)

In the UK, AFOs are provided to children who need them free of charge through the NHS. While solid AFOs can be made out of polypropylene or carbon fibre, this project will focus on polypropylene AFOs which are regularly given to children with CP and which can easily be adjusted for patient benefit and to incorporate usage sensors. Polypropylene AFOs can be also customised and coated with a decorative print to increase their attractiveness to children, and Trusts have a range of patterns that the child can choose from (Appendix 3).

2.6 Clinical reasons for AFO compliance

AFOs also contribute towards improving the user's independence and participation with activities during their daily life by supporting users' mobility and improving gait and walking ability (Osam et al., 2019), a side effect of which is often an enhanced quality of life and their mental and physical wellbeing. Furthermore increased mobility levels can also indirectly benefit patients as a lack of physical activity can often initiate a downwards spiral where low fitness contributes to increased difficulty in carrying out activities which can reduce activity and fitness further (Nooijen et al., 2014). This was somewhat reinforced by a study which noted a correlation between children walking and having a reduced chance of becoming non-ambulatory: children who walked in place of using a wheelchair had an 11% chance of becoming non-ambulatory, while those who used a wheelchair had a much greater chance (34%) of becoming non-ambulatory (Day et al., 2007). Despite the benefits that AFOs can bring to children, many people stop wearing them or report low levels of usage during adolescence (Wingstrand et al., 2014); low satisfaction levels with AFOs have also been reported in the under-18 age group (Holtkamp et al., 2015). Furthermore, there is also some evidence that that children with CP often lose functional ability through adolescence and early adulthood (Andersson and Mattsson, 2001; Krakovsky et al. 2007), though it is not clear whether this is linked to use of AFOs. An unworn AFO can offer no support to the child, and patients refusing to wear the device can potentially experience problems in the future, and so it is important that problems with compliance are addressed. In addition to the personal issues associated with not wearing AFOs, the devices also represent an investment on a societal level. Every prescription and fitting of an AFO costs hundreds of pounds and many hours of clinical professionals' time. If an AFO is unused, not only does the individual not gain the potential benefits of the equipment, they also waste the time and money of the NHS. In an era where funding for the NHS is already stretched, ensuring that all resources are used efficiently and effectively is essential.

With poor usage and device satisfaction already established in this area, adolescence is a critical point of time for further research in order to understand patients' perceptions and target interventions for future practice. Developmentally, adolescence also marks a point where individuals begin to lay the foundations for behaviours which will last into adulthood, and so targeting non-compliant behaviour here allows clinicians to help their clients develop positive behaviours for life (Nooijen et al., 2014), maximising the benefit to the patient and fully utilising the resources of the NHS.

It has been suggested that many factors contribute towards an individual's compliance with medical devices (Basford & Johnson, 2002), and other research has suggested that perception and empowerment can improve the likelihood that an intervention will be successful and produce positive compliance rates (Desmond & McLachlan, 2002). Further research into factors which influence compliance is essential to increase understanding of the elements which impact on young people's likelihood to wear their AFOs and it is hoped that this understanding will provide the foundations for future interventions to positively impact on the compliance levels of young adults with CP in the future.

2.7 AFO usage

Conflicts between adolescents' opinions and medical suggestion often means that AFOs aren't worn as directed and there is often a compromise in their use between clinicians, parents and children rather than complete compliance with the recommended usage (Øien et al., 2016). Despite attempts to encourage children to use AFOs by offering a choice of attractive designs, AFO use in under 18s is often much lower than recommended (Wingstrand et al., 2014; Basaran et al., 2016; Schwarze et al., 2019) though use does vary across age (Wingstrand et al., 2014) and between individuals (Schwarze et al., 2019). Current literature suggests that there are a number of reasons why patients choose to not comply with clinicians and wear their AFOs as directed (Basford & Johnson, 2002) but these reasons have not been thoroughly investigated. Yet these reasons for choosing to not comply with usage suggestion are likely to be especially relevant for children moving through adolescence and the associated social and physical developmental changes (Piaget, 1955) and identity formation (Erikson, 1968) which occur during this period. Indeed, adolescent noncompliance is already a well-established phenomenon in a number of medical areas and has already been highlighted as a problem which requires further investigation (Windebank & Spinetta, 2008).

It is also important to recognise that the perception of the device will vary between age groups. Perception is influenced by the lived experiences of the individual and the environments that they interact with and so what is considered attractive or useful to one social group (or age group) may cause problems with usage in another. The position of AFOs, and assistive devices in general, stands between medical device and social object in relation to the user; its visibility to others means that it stands, to a certain extent, as a symbol of the disability of the user, or a social marker of their difference from the other children in their class (Øien, Fallang, & Østensjø, 2016). The significance of this varies between individuals, but for some, it is enough to encourage non-use of the AFO even where the device offers significant physical benefit to the user (Sugawara et al., 2018).

Interestingly, the ease with which an AFO can be removed gives children an element of control over their compliance, particularly where parents are not present, and this creates an interesting dynamic where children are able to adapt and create their own rules for its use to allow them to engage in desired activities or as best fits perception of the situation, e.g. wearing them when sitting on a chair but not when sitting on the floor, or wearing them in the classroom but not to play football (Øien et al., 2016). This social interaction influence can play a significant role in the willingness of children and adolescents to comply with recommended usage yet is minimally represented in the literature.

2.8 Summary and aims of the project

AFOs have the potential to make a significant impact on the mobility and quality of life of children with CP, both during their childhood and later during their adult lives. Research that indicates reduced AFO usage by young people (Wingstrand et al., 2014), and others which discuss the link between not walking and becoming non-ambulatory (Day et al., 2007) highlight an area which would benefit from research to develop a greater understanding of the factors which are responsible for these behaviours. The current literature suggests that there are a number of factors which influence patients' propensities to wear their AFO (Basford and Johnson, 2002), though there is very little work which investigates the psychological elements which can impact on this. It is only by understanding the elements which influence a patients' actions that effective interventions can be introduced to improve AFO usage; this is particularly important where influencing factors may conflict with the current perceptions of medical professionals (Swinnen et al., 2018a; Holtkamp et al., 2016). If compliance rates are increased then the literature suggests that AFOs can have a positive impact on the mobility and independence of the children who need them, both in the short term and in later life, this could lead to a substantial benefit to the lives of a great number of people.

Understanding the factors which affect individuals' willingness to use the AFO is an important step to producing beneficial assistive devices for patients and ensuring that they are used effectively. This project will investigate the experience and perceptions of AFOs by children and adolescents with CP to understand the factors which influence their compliance. This will take place through the objective measurement of AFO usage, but also through the subjective exploration of the experiences and perception of young AFO users and their families. A combination of quantitative and qualitative methodologies will be engaged to explore these areas, and together these will provide a holistic view of the behaviours behind compliance. It is hoped that this will then provide insight into efforts that clinical staff can engage to promote AFO compliance in the future.

To thoroughly investigate the factors which influence AFO compliance in children and adolescents with CP, the following objectives will be investigated:

- To explore the existing literature surrounding compliance with AFOs with an emphasis on compliance and usage in young people with CP and factors which may influence this.

- To determine the most effective method to monitor usage of AFOs outside of the clinical environment.

- To assess the functional effect of AFOs on children with CP through the comparison of gait with and without AFOs.
- To discover the AFO compliance rates of children with CP.
- To explore the experiences and perceptions of AFOs from the perspective of the user in order to determine factors which influence compliance.
- To investigate the perceptions of pathological gait and AFOs/assistive devices by able-bodied, mainstream children in order to provide context for the user's experiences and perceptions.

To meet these aims and objectives, a literature review was carried out and the methodology for a number of studies were developed. However, due to the onset of the Covid-19 pandemic, the practical elements of this study proved impossible, see chapter six.

Chapter Three: Literature review: AFO compliance

3.1 Introduction to compliance

One of the most common assistive devices currently administered to children with cerebral palsy (CP) is an ankle-foot orthoses (AFO), which is a structure that supports from below the knee to around the ankle and under the foot and provides stability and support to facilitate more efficient walking (Wingstrand et al., 2014). Assistive devices, particularly AFOs, can be life changing for children with disabilities because they allow them to keep active, engage in daily activities, and develop their independence (Osam et al., 2019), reducing the chance of further physical deterioration (Nooijen et al., 2014). As the symptoms of CP will be present and continue to require treatment across the patient's life (Jankowska et al., 2015), it is important to establish an effective therapeutic intervention early on and ensure that the patient is using them. This enables clinicians to help patients manage their condition and prevent any deterioration which could lead to loss of quality of life or physical ability (Nooijen et al., 2014).

There are large amounts of research taking place which investigate the efficacy of AFOs and the structural and mechanical benefits that they bring to patients but much less research which investigates compliance, yet the success of an intervention is directly linked to its use. An AFO can have no effect and offers no support to a person who isn't wearing it, and any benefits may also not occur if the AFO is not worn for the prescribed amount of time (Tardieu, Lespargot, Tabary, & Bret, 1988; Schwarze et al., 2019). Despite usage being a significant factor of the impact of AFOs, research into patient compliance with walking devices is much less frequent than research into efficacy.

Patient compliance refers to patients' conformation to the instruction of a medical professional regarding a medical device or prescription (Swinnen & Kerckhofs, 2015). In the case of AFOs, it refers not only to wearing an AFO but also wearing it for the directed amount of time. Compliance is a complex concept as it is influenced by a number of interconnecting factors (Basford & Johnson, 2002), but use of an AFO in line with medical recommendation is essential for the health and wellbeing of the patient. Non-compliance may contribute to the deterioration of a patients' condition which can impact on their independence, quality of life, and wellbeing (Day et al., 2007; Chan et al., 2014; Nooijen et al., 2014), furthermore any devices which are not worn also represent a loss of funds from the NHS for wasted time and devices (Swinnen et al., 2015/2017; Osam et al., 2019) and can reduce the accuracy of research carried out on patient data (Hunter et al., 2008). With the potential for noncompliance to have significant effects on the patient and the wider health service, it is essential that compliance is thoroughly investigated to maximise medical device use in the future.

Compliance varies across age groups, particularly during childhood and early adolescence. Children of primary school age (five-11) have some of the highest AFO usage, with the greatest use displayed by five year olds (Wingstrand et al., 2014). Despite the highest rates of use, there are several papers which report children disliking their AFO or wearing it out of obligation not personal choice; the latter is perhaps best expressed by a quote from an interview with a child in their first year of primary school, and a quote from an interview with a parent:

> *"I can. I can use it when I want. No, actually, I cannot (lowering the voice). I have to use it […] I have to use it at school, six hours a day*."(Øien, Fallang, & Østensjø, 2016)
>
> "*We've compromised, he's said no AFO, I said I wanted an AFO, so we've compromised, and we want him to wear it only during school hours*."
> (Hayles et al., 2015)

Papers which question parents about their children's experiences feature positive reports from parents regarding the walking devices' appearance and the effect on their children's walking, but many comment that their children, although they wear the device regularly, do not like to use their AFO (Ireno et al., 2019). Compliance often becomes more problematic as the child ages (Eddison, 2018). As children develop through adolescence AFO compliance decreases, particularly between 14 and 19 years old, with 19 year olds exhibiting the lowest percentage of usage out of all walking age groups (Wingstrand et al., 2014), and it has been documented that adolescents are often reluctant to wear their AFO (Hayles et al., 2015). This correlates with findings which show that children with CP often lose functional ability through adolescence and early adulthood (Andersson & Mattsson, 2001; Krakovsky et al., 2007), though no causative link has been made. This noncompliance has also been observed in a range of other medical areas (Muscari, 1998; Nevins, 2002; Petrini & Seuser, 2008; Windebank & Spinetta, 2008; Al-Jewair, Suri & Thompson, 2011; White, Bannerman & Gillett, 2016) and identified as a significant problem which needs further research and action (Windebank & Spinetta, 2008).

Adolescence is a period of transition, with a number of physical, mental, sexual, and social developments occurring during this time (Nevins, 2002; Petrini & Seuser, 2012). The transition into early adolescence and teen years, notably the start of secondary school, marks a point at which many children are given greater levels of independence and increased levels of control over their actions and appearance. Developmentally, it is a time when children transition to adults and undergo psychosocial development and identity formation (Erikson, 1968), and begin to develop symbolic reasoning and complex critical thinking (Piaget, 1955). These developments can conflict with challenges linked to health conditions (Petrini & Seuser, 2008), or influence AFO usage and contribute to the reduction of compliance in this age group. Further research surrounding factors which affect usage and compliance could help to improve the physical abilities of children with CP and provide support to enhance their quality of life, wellbeing, and independence (Day et al., 2007; Chan et al., 2014; Nooijen et al., 2014).

Adolescence has been identified as a significant age group to target for research and interventions, particularly in individuals with CP, because it can influence behaviour in later life (Nooijen et al., 2014). However, despite problematic compliance levels in adolescents (Wingstrand et al., 2014), and findings showing that the adolescent age group (under 18s) has the lowest satisfaction levels regarding AFOs (Holtkamp et al., 2015), there is surprisingly little research which investigates adolescent compliance in detail, or which explores elements that influence their behaviour. AFO compliance can be broken down into two key elements: the time that the AFO is used, compared with the recommended usage time, (here referred to as ‘usage’); and factors which affect that usage. Although the two facets are intertwined and both are essential for a holistic understanding of compliance, they are typically investigated separately in the literature. This can be problematic: knowing how long the AFO is worn for but not understanding what affects that time makes it difficult to improve wear time in the future, while only understanding factors which affect usage are useless if the extent that they influence the usage is not known. A literature review will be undertaken to investigate AFO compliance in children with CP. In recognition of the split in the current literature regarding this topic, the literature review will be made up of two parts: AFO usage, and factors which influence AFO usage. This will allow the most relevant research to be explored in depth and support a thorough understanding of compliance.

3.2. Usage

One of the most difficult elements with researching compliance is accurately determining the patients’ adherence to the prescribed usage time, that is: the extent that patients are wearing their AFOs outside of the clinical environment. Although many medical professionals are aware that patients do not always adhere to the recommended instructions or directed usage (Basford & Johnson, 2002), data regarding the amount of usage are typically limited to anecdotal reports of orthotic usage from patients or caregivers which can be inaccurate and is a problematic foundation on which to build future medical recommendations (Vandal, Rivaro & Bradet, 1999). As research about AFOs increases, effective methods to collect usage data are also being investigated, though the current literature is still relatively sparse (Schwarze et al., 2019).

A literature review was carried out to investigate the levels of AFO compliance exhibited by adolescents with CP. Research databases EBSCO, Google Scholar, and Web of Science were used to find papers relating to AFO compliance or usage in children or adolescents using the search term: "(child* OR "young adult" OR adolescen*) AND (CP OR "cerebral palsy") AND (ortho* OR "ankle foot" OR AFO) AND (compliance OR usage)"; during later stages of searching, the terms were adjusted to include "objective" or "subjective" measurements. Papers included in the literature review were selected based on relevance according to title, abstract, and conclusions. Significant papers referenced in already selected papers were also included if they had not appeared in the initial research database searches.

The initial search criteria revealed few papers which investigated the orthotic compliance of adolescents with CP so the criteria were extended to include compliance rates of other orthoses or orthopaedic walking devices. Papers were prioritised where the orthosis was removable, similarly visible to peers, and which featured participants aged between 10 and 16; matching the demographics or research techniques of this project where possible. A common condition which featured in these search results was idiopathic scoliosis, a condition where patients exhibit significant curvature of the spine, a number of papers of which featured monitoring of spinal orthosis usage in children and adolescents.

This literature review will look at the current literature which investigates compliance surrounding AFOs and other orthotic devices, starting with subjective methods of measuring usage before moving on to objective methods and then studies which compare the two. I will consider the findings of the papers regarding compliance levels and assess the disadvantages and benefits of the different methods of measurement, considering which will be most relevant for this study. In this literature review I will be defining 'subjective methods' as those which require the patient to record and deliver the data about their usage levels, for example through questionnaires/surveys or interviews; while I define 'objective methods' as those where the usage data are recorded independently of the patient, using a sensor or device to measure the amount of time that the orthosis is worn. Factors which affect compliance will not be addressed in this literature review, but in the review following this.

3.3 Literature review: AFO usage

One of the largest problems with the literature surrounding measuring usage of walking devices and orthotics is the plethora of methods and definitions that individuals have used to collect their data. Some studies report rates of compliance ranging from 20% (Vinci & Gargiulo, 2008) to 92% (Dijcks et al., 2006) of people using their AFOs, while other studies report that the average patient uses their AFO for 33% (Vandal, Rivaro and Bradet, 1999) to 65% (Nicholson et al.,2003) of the recommended time. The diversity of definitions of compliance between studies makes it difficult to compare the findings but this predominantly stems from the use of different methodologies to investigate the topic: those which engage subjective measurements to investigate usage and compliance, and those which use objective measurements.

Subjective measurement

At a glance, literature that uses subjective measurements suggests that compliance with medical recommendation regarding orthotic devices is relatively high, with fairly consistent results across papers irrespective of device or condition. Authors who used surveys to ask patients about their orthoses, their satisfaction and actual use, have found that the majority of people who wear lower limb orthoses use them on a regular basis or as expected and are generally satisfied with them; with many users also noting how crucial AFOs are for their mobility and independence (Holtkamp et al., 2016; Sugawara et al., 2018). Basaran et al. (2016) noted that 60.6% of users who bought their device use lower limb orthoses on a regular basis, with an additional 22.7% (total 83.3%) using them irregularly or who stopped only after a period of use. This was similarly reported in a study of 33 lower-limb orthoses patients, 84.8% of whom were AFO users: 64% wore their orthosis every day with the remaining 36% (total 100%) wearing them multiple times a week (Swinnen et al., 2015). Furthermore, a study investigating spinal cord injury patients with lower limb orthoses (most commonly hip-knee-ankle-foot orthoses, HKAFO) identified that 67.7% used the orthoses every day with an additional 6.5% of patients using them at least once a week (total 74.2%) (Koyuncu et al, 2016), findings that were also reinforced by similar studies surrounding orthopaedic shoes, where 81% of people were found to wear orthopaedic shoes between four and seven days a week (Van Netten et al., 2010). One of the few exceptions to these findings was a study by Vinci & Gargiulo (2008), who investigated AFO compliance in patients with Charcot-Marie-Tooth disease, who found that only 20% of the participants (5 patients) use their AFO, and 48% (12ppts) hadn’t gone to be fitted for an orthotic at all. The findings in these papers are largely consistent and suggest that the majority of patients who need lower limb orthoses use them to some degree, yet whether this accurately reflects the usage of patients is questionable. These papers treat compliance and usage as a discrete variable: either worn, or not worn, rather than a continuous scale: worn all the time through to worn none of the time. A lack of clear definition surrounding usage also opens the question to being interpreted in a number of different ways by the participant: being used right now, being used regularly, being used occasionally, used as directed etc. While this produces positive appearing statistics, it offers little benefit for research because it fails to identify whether the orthoses are being worn for the directed amount of time or whether they are being worn correctly, and with a lack of clear definition of usage, it is likely that different interpretations of the question could contribute to an artificially high representation of orthotic wear. Furthermore these results are collected following usage rather than during the period that the AFO is being worn. Not collecting data continuously throughout AFO use also relies on patients' memory and their ability to recall events accurately and without being affected by external influences, something which has been proven to be weak in people (Loftus & Palmer, 1974). This may also have contributed to artificially increasing the representation of usage.

In interviews and focus groups, where patients could give longer free responses and clarify their answers, responses about orthosis use were similarly positive but less specific regarding usage than those in the questionnaires. Reports in a paper by Øien, Fallang, & Østensjø (2016) supports the findings of the surveys, suggesting that walking devices are used at school every day by young patients in primary schools, while in other interviews, users emphasised the essential nature of their AFO, saying that they were immobile without the device (Holtkamp et al., 2016). A focus group study with MS patients who use lower limb orthoses (of whom 50% used AFOs) said that while there was no homogenous view amongst the patients, that usage depended heavily on the environment and external factors that each patient was exposed to (Swinnen et al., 2018a).

While focus groups and interviews provide a means to access detailed information from a patient, they are a more problematic way to collect data regarding usage, predominantly because they collect data from an invested party at one point in time rather than over a prolonged period. Like the surveys, not only are the patients asked to remember events and timings which occurred in the past, they are also asked to comment on things which they may wish to present in such a way that they please (or do not disappoint) their clinicians, both of which increase the likelihood of reducing the accuracy and validity of the data collected. The nature of interviews, however, allows participants to prioritise in depth discussion surrounding points which they deem important to the project. This, although it makes them weaker methods for measuring usage, makes interviews and focus groups an excellent method for research surrounding perception and experience. Indeed all of the papers mentioned here focused on usage only as a supporting finding for much wider discussion surrounding satisfaction and factors which influenced usage, with very useful results.

Use of subjective methods of measuring compliance suggest that most patients use their lower limb orthotic devices, and a substantial number use their device on a regular basis. However, there are two key problems with using these methods for this type of research, notably that it relies on the patient, an invested party, to provide the information about their usage; and that it relies on a very clear definition of usage. A significant risk of any subjective means of measurement is that patients and caregivers answer ideally rather than accurately. Where there are guidelines suggested by medical professionals there is an incentive to provide an answer in line with the medical recommendations. A combination of bias on the part of the patient or caregiver, and reliance on memory to provide usage data results in the times relayed to the clinician and the actual usage values are often different (Jahnsen et al., 2004; Morton et al., 2008; Maas et al., 2018). This can contribute to an overall overestimation of the usage. By adjusting the research question to investigate how much a device is being used and by changing the methodology to a method of measurement which uses an uninvested third party to collect the data instead of the patient reporting for themselves, researchers not only gain more consistent results between patients but it becomes easier to compare studies post publication.

Objective measurement

Objective measurement of compliance acts as a means to remove patient partiality from data collection, providing a more reliable way to determine whether or not AFOs are being used as recommended. Typically, data-logging sensors (either pressure, temperature, or both) are inserted into the device and take regular readings to determine whether the orthosis is in use or not throughout the day. This produces a detailed record of use across the day that can be used to calculate overall usage and which can also be further analysed to determine wearing patterns to indicate the presence of usage-influencing factors.

A recent study by Schwarze et al. (2019) used temperature sensors to determine the amount of time that children aged between four and ten with bilateral spastic CP (GMFCS level 1-3) wore their dynamic AFOs (DAFOs) and modular shank supply (MSS). They reported a notable difference between the prescribed time that patients were recommended to wear their AFOs and the actual amount of time that they were worn. Descriptive statistics were carried out and identified that 1 in 6 participants wore their DAFO as recommended, whilst 1 in 8 wore their MSS as recommended, and on average the orthoses were worn for 55.4% of the prescribed time (54 days out of 97.5 expected). These compliance levels are not dissimilar from other, similar studies: a measure of the compliance levels of nine female adolescents (average 14.2 years old, SD 1.5) with spinal orthoses using temperature sensors over an average of 5.4 weeks, found that patient compliance averaged at 67.5% (between 19.0% and 97.1%, an average of 15.4 hrs/day out of the recommended 23 hrs/day) (Helfenstein et al., 2006); while Nicholson et al. (2003) reported that their patients averaged 65% compliance with directed use (range 8 to 90%).

Some papers used the time data to further assess usage by identifying common usage patterns. Helfenstein and colleagues (2006) and Nicholson et al (2003), who investigated spinal orthosis usage in idiopathic scoliosis patients, noted that most non-compliance occurred during the day. The study by Schwarze et al. (2019) used the data set produced by the temperature sensor to investigate usage time in even greater detail. One of the most significant behaviours observed in the participants was different wearing times between the weekdays and weekends with orthoses being worn, on average, more often during the weekdays (63.25% of the expected amount: 44.17 days out of 69.83 expected), while weekend use was only 35.5% of the expected amount (9.83 days out of 27.67). Further analysis of the distribution of orthosis wear noted that patients who had a low adherence to the recommended usage tended to only wear the brace at night, and that in all users, there was no difference between wear at school or during free time, though there was no follow up research which investigated reasons for these differences in behaviour. When the days that the orthotics were worn were investigated separately, the mean wearing time of the participating children was closer to the recommended usage, suggesting that in general, although the orthoses are not being worn enough (none of the participants wore their orthotics for every day of the study), on the days that they are worn, they are being worn as prescribed.

One of the main takings from the Schwarze et al. (2019) study was the heterogeneity between participants' usage. Despite being selected to form a homogenous participant base, all of the children wore their AFOs for different amounts of time, and many exhibited patterns of use across the week. These data raise two interesting implications about factors that influence AFO use. Firstly, the presence of usage patterns across a week (day/night, weekday/weekend) supports the suggestion that different environments or activities will affect AFO usage; secondly, the heterogeneity of the usage data highlights that patients will all be uniquely affected and influenced by these environments, activities, and the social world in which they live. While there may well be trends across participant data and similar responses from a majority, patients will always have different responses to their AFOs, irrelevant of the homogeneity of their age or condition; these factors may form a usage pattern if they are time dependent. The exact reasons and factors which cause these differences, however, cannot be determined through objective measurement and require in depth communication with the patient themselves to be fully understood.

Objective measurement using temperature or pressure sensors is consistently reported as being an accurate, mostly reliable method to investigate compliance (Helfenstein et al., 2006; Hunter et al., 2008; Pauls et al., 2013; Chalmers et al., 2015; Schwarze et al., 2019). In addition to this, it allows for detailed investigation of the wearing distribution, enabling statistical analyses to compare use between different days or environments which opens the possibility of identification and further research into factors which affect AFO usage. However, despite the promising findings from using sensors to measure usage, there have been some questions raised regarding whether the data collected in studies accurately represents standard use. When this was investigated in detail, papers which investigated whether knowledge of the purpose of the sensor affected usage reported the following results: that usage was not affected in patients who knew their compliance was being monitored (Pauls et al., 2013), that compliance can be estimated from the data after a fortnight and as such, after an initial period, is not noticeably influenced by the presence or knowledge of the sensor (Helfenstein et al., 2006), and there is a significant difference in compliance between patients who had been uninformed about the purpose of the sensor (56.5% use) and those who were (85.7%) (p=0.029), with those who were informed about the sensor showing usage time amounting to an average of 5.24 hours a day more than those who were not (Miller et al., 2012). With some suggestion that patients may alter their behaviour if they are aware that they are being monitored, carrying out studies, there are some questions about the extent that the data reflects normal use. However, a lack of consistent finding in studies which investigated differences between informed and uninformed patients, and similar usage values reported in the Miller et al., (2012) blinded group, average of 56.5% use, and the non blinded patients in the Schwarze et al. (2019) study, average of 55.4%, suggest that it is not necessarily a confounding variable which needs to be accounted for, though it should continue to be considered.

There have also been some concerns about the technology used as part of objective measurement, either with the sensor or with the data recovery process. Schwarze et al. (2019) described a large amount of data loss due to technical problems with the device, amounting to 40% of DAFO data and 20% of MSS data; a problem similarly seen in a study by Maas et al. (2018). A study by Hunter et al., (2008), which investigated the validity of some sensors used for objective measurements, noted that the pressure sensors which they used had a tendency to underestimate wear time while their temperature sensors had a tendency to slightly overestimate wear time. Other studies described problems with data collection if the orthosis was not held tight to the body and the sensor was not in direct contact with the skin (Chalmers et al., 2015). Few papers reported no problems with sensor-based methods of data collection so it is not a flawless system, however, recommendations to use more than one type of sensor may remedy many of the problems and reduce the impact that data corruption may have on the research.

Comparison of subjective and objective measurement

A number of papers have sought to compare the results from objective and subjective methods of monitoring compliance to determine which method gives the most valid result. These often identify a significant discrepancy between the results of the two methods.

In a study comparing the data about AFO compliance collected via parent-report, and objective measurements collected by temperature sensors, Maas et al. (2018) identified large differences between the number of hours of use reported by parents of children with AFOs, and the number of hours recorded by the sensor. The sensor took a reading every 15 minutes and temperature shifts beyond 3°C were used to define usage. Parent data was collected through questionnaires sent out every four weeks. Wearing time was generally lower than suggested, and there was nearly always a difference between parents' perceived usage of the KAFO and the objective measurement of use, though these differences varied with each participant most reported greater use than recorded.

These findings were similar to those seen in an older study investigating compliance in girls aged between ten and 16 who used spinal braces to help with idiopathic scoliosis (Vandal, Rivaro, and Bradet, 1999). Objective measurement using a sensor was compared to reports of use through a questionnaire-interview and showed significantly different results ($p<0.05$). Participants suggested that their own compliance was, on average, 88%, while the devices reported compliance to be an average of 33%. Another study investigating nonadherence in idiopathic scoliosis patients compared the data collected from a temperature sensor with the compliance levels as perceived by the patients, and their parents, physicians, and orthotists. Patients were reported as wearing the brace for just 47% of the time required. Perceived times varied between the individual reporting them with physicians and orthotists estimating the lowest times (64% and 66% respectively) and parents and users reporting usage levels of 72% and 75% respectively (Morton et al., 2008). Finally, a paper by Helfenstein et al (2006) found a great difference between the two modes of measurement, noting that objective measurement of compliance (67.5%, range 19.0%-97.1%), was lower than subjective measures (94.4%, range 75% to 100%) on average by 88.3% (range 2.4% to 427.3%); which showed very similar findings to Nicholson et al., (2003) who reported that their patients generally overestimated their usage levels by 150% (SD 50%). While the compliance values vary, the discrepancy between reported and measured usage is consistent across papers. All of the studies which compared subjective and objective methods of measurement concluded that patients are unreliable sources of usage data and stated that objective means of data collection offer the most accurate way to monitor compliance. Patients and sometimes their parents consistently report higher usage levels than are measured objectively, though this difference has been reported to reduce if patients are aware that their usage is also being recorded (Pauls et al., 2013). Accurate data regarding usage is essential to beneficial prescriptions and research regarding efficacy or efficiency of devices if the measurement is inaccurate then it can lead to damaging conclusions being drawn and problems in the future. It is therefore important to use the most accurate method possible to measure usage. Objective measurement removes human error, subjectivity, and bias from the data collection process allowing for the most accurate and reliable data to be compiled.

3.4 Conclusion

Literature investigating AFO usage in adolescents with CP is scarce but when combined with other literature which investigates orthotic compliance, it makes up a strong foundation for future research. A literature review of these papers identified an average usage value for similar patients and walking devices and highlights suitable methods to utilise in this project.

Compliance varies across the studies, but the papers generally agreed that over half of patients wore their device regularly, those who had their usage monitored used their orthosis less than prescribed, though this was notably varied between participants. Papers which utilised subjective measurement techniques reported that between 20 and 92% of people use their walking orthotics to some degree, with 53.1% using them regularly or every day. Studies which used objective measurement techniques measured patient compliance rates to be between 33% and 68%, with most reporting that patients use it an average of 62.6% of the prescribed time. Most papers noted that there was considerable heterogeneity between individuals within the data, and that there was also some support for environmental factors affecting compliance levels.

Objective measurement of usage using temperature or pressure sensors has been shown to offer a more accurate method to determine wearing time than using subjective methods. Objective measures remove people from the data collection process, creating an impartial data collection mechanism, and when combined with a continuous data collection mechanism, produce results which are more reflective of the actual usage. Data collected over a prolonged period of time also allow for further investigation into patient usage, allowing for an analysis of wearing habits which offers an opportunity of further investigation into influencing factors (Rahman et al., 2010) which is essential for an investigation into compliance. Temperature sensors are widely agreed upon as being both a reliable and effective method to accurately measure usage (Hunter et al., 2008; Rahman et al., 2010), with some lesser support also present for pressure sensors (Hunter et al., 2008). While objective measurement allows researchers to accurately measure AFO usage and provides insight into the wearing habits of patients, device usage is only one facet of compliance. Objective measurement through sensors cannot collect data surrounding reasons for use or removal, nor can it determine patients' opinions regarding the device, meaning that, if used in isolation, it cannot be used for an in-depth analysis of compliance. To be able to identify any significant elements which might be influencing compliance levels and to use that to identify intervention methods, a combination of methodologies - in a mixed methods study - which incorporated both objective measurement of usage and qualitative investigation of experience and perception, would need to be engaged.

3.5 Factors which influence usage

The second element of compliance concerns the factors which affect whether or not an individual chooses to comply with clinical recommendation; in this case, whether or not children with CP wear their AFO. As seen above, the usage of lower limb orthotic devices is generally lower than recommended and has been reported to be particularly low during the adolescent period (Wingstrand et al., 2014). While adolescence can be a difficult period, with rapid growth complicating symptoms of CP, as a lifelong condition which will require therapy throughout (Jankowska et al., 2015), it is important to encourage people who would benefit from wearing an AFO to establish wearing habits early on in life in order for them to gain maximum benefit from the device.

Compliance is a complex topic influenced by a number of factors (Basford & Johnson, 2002), and compliance in adolescence is further affected by additional age specific elements (Petrini & Seuser, 2008). Despite the magnitude of the subject, it is important to identify and understand factors which influence compliance and patients' choices to engage with beneficial behaviours (White, Bannerman & Gillett, 2016). People are unique, and even those who appear similar on paper will have very different approaches and contexts which influence their decisions, thus it is important to remain aware that individuals may not be affected by all of the factors discovered or may have other factors which are specific to them.

There is some support for the suggestion that if an AFO is adapted to meet the needs of the user, it can improve their wear time (Vinci & Gargiulo, 2008). Investigating factors which influence compliance, particularly through interviews and focus groups which allow patients to expand on their experiences and perceptions, provides information about elements that can be used to improve compliance (Eddison, 2018). These can then be used in collaboration with communication with the patient, to develop a stronger understanding of the factors which influences device usage, and can be used to make changes and improvements favourable to the device user to help increase the wear time which should allow the AFO to support the user's gait and walking efficiency (Wingstrand et al., 2014). A literature review was carried out to investigate factors which may influence AFO usage in children with CP. Papers from the usage literature review which also discussed factors that may affect usage were included in this literature review. A further literature search was carried out using research databases: Web of Science, EBSCO, and Google Scholar using the additional search terms: "abandonment", "factors", "satisfaction". When a number of papers were found discussing adolescent noncompliance in medical areas, further searches surrounding "Adolescent compliance" were carried out to fully investigate the literature which has investigated the factors that can affect patient adherence to medical advice. Although priority was given to papers which investigated compliance surrounding AFOs and, where possible, compliance of children with CP using AFOs, research which investigated adolescent noncompliance in other lifelong disorders, e.g. coeliacs disease or haemophilia, was also considered to more broadly investigate the elements which impact adolescent compliance.

3.6 Literature review: factors which influence usage

A literature review identified a number of factors which influence compliance with medical recommendation or AFO use. These findings are listed and summarised below.

The AFO

One of the most prominent factors which affects people's AFO usage levels is the AFO itself. Discussion about the device and the impact that it has on the user and their life was relatively common across the literature and varied wildly from people reporting the positive elements that it brings to their life and their dependency on it, to others discussing multiple aspects which they found problematic. In a survey about perceptions of assistive devices, 78% of whom were AFO users, only 29% of respondents said that they would not change their device (Swinnen et al., 2018). A summary of the elements of AFOs which affect patient usage are detailed in Table 1, with the most frequently referenced elements listed at the top.

Table 1 - A summary of the AFO elements which affect patient usage, ordered by number of papers who mention it.

Element	References
User experiences pain, excessive discomfort, or skin irritation due to the device.	Muscari, 1998; Dijcks et al., 2006; Garralda et al., 2006; Vinci & Gargiulo, 2008; Magnusson at al., 2013; Squyer et al., 2013; Chen et al., 2014; Maas et al., 2014; Magnusson, et al., 2014; Oien et al., 2014; Swinnen & Kerkhofs, 2014; Holtkamp et al., 2016; Mauricio, Slepen & Rosenbaum, 2017; Van der Wilk et al., 2017; Swinnen et al., 2018a; Swinnen et al., 2018b; Ireno et al., 2019
The aesthetic or cosmesis of the device.	Garralda et al., 2006; Waldron & Layton, 2008**;** Ghoseiri & Gahramian, 2011; Swinnen & Kerckhofs, 2014; Holtkamp et al., 2015; Eddison, 2018; Swinnen et al., 2018a; Swinnen et al., 2018b; Ireno et al., 2019
Function /perceived function of the AFO.	Ghoseiri & Bahramian, 2011; Squyer et al., 2013; Chen et al., 2014; Van der Wil et al., 2017; Swinnen et al., 2018a; Swinnen et al., 2018b; Ireno et al., 2019;
Problems with the AFO impairing certain activities e.g. sitting on the floor, driving, or difficulty walking while wearing them.	Garralda et al., 2006; Holtkamp et al., 2016; Øien, Fallang, & Østensjø, 2016; Sugawara et al., 2018; Swinnen et al., 2018a; Ireno et al., 2019; Schwarze et al., 2019
The quality or suitability of the device.	Ghoseiri & Bahramian, 2011; Holtkamp et al., 2016; Sugawara et al., 2018; Osam et al., 2019.
Damage to clothes caused by velcro straps on the AFO, or other problems with the fixation methods, e.g. durability.	Ghoseiri & Bahramian, 2011; Swinnen et al., 2018b; Swinnen et al., 2018a; Ireno et al., 2019.
AFO considered too heavy.	Ghoseiri & Bahramian, 2011; Swinnen et al., 2018b; Ireno et al., 2019.

The device doesn't fit well or has uncomfortable dimensions.	Djicks et al., 2006; Ghoseiri & Bahramian, 2011; Swinnen et al., 2018b.
Difficulty with putting on/removing/using the AFO.	Ghoseiri & Bahramian, 2011; Swinnen et al., 2018a; Swinnen et al., 2018b.
Difficulty finding shoes that are compatible with AFOs and that are aesthetically compatible with the patient's wants.	Van der Wilk et al., 2017; Swinnen et al., 2018a; Swinnen et al., 2018b.
Concerns about the safety of the device	Mauricio, Slepen & Rosenbaum, 2017; Swinnen et al., 2018b.
Child exhibiting dislike of the AFO.	Øien, Fallang, & Østensjø, 2016; Ireno et al., 2019.
The ability of the patient to function acceptably without the AFO.	Vinci & Gargiulo, 2008; Peaco et al., 2011.

Most of the factors listed as influencing AFO usage are elements which users find problematic and may, either in isolation or combination with other factors, reduce the amount that AFOs are worn by patients to some extent. There are some, however, which have a positive influence on usage, and others still which can affect compliance positively or negatively according to the perception of the patient.

The more commonly referenced factors in the table above tended to be the ones of greatest complexity and reliance on personal interpretation of the device itself. The aesthetic or cosmesis of the device, for example, is regularly discussed in the literature but with a variety of opinions and outcomes. Generally, these papers suggest that aesthetic has a two-way influence over user compliance: that where the AFO is considered to be unattractive it is likely to influence usage negatively, and where it is considered attractive it might promote additional use. This was emphasised in a paper which pointed out that the compliance levels were improved where the user had an opportunity to choose the assistive device and decide on its customisation (Waldron & Layton, 2008). The extent that this factor may affect usage, however, is always affected by the degree of importance that the user places on aesthetic over functionality or other factors. Functionality, quality, and suitability are similarly two sided with their influence, with patients suggesting that where these elements are perceived to be suitable or beneficial, they will promote increased use, while a failing on any part would lead to poor compliance.

None of the referenced papers disputed any of the claimed influence, though commonality and significance of the factors did vary across the reports. This is to be expected of any subject which is so intrinsically linked to personal factors and mimics the diversity of usage between the participants which was discussed in the usage literature review. It is also notable that many of the factors listed above are elements which the NHS is already aware of and tries to address for patients. Pain is minimised by adaptive moulding of the AFO and the insertion of soft foam pads on areas that rub, and soft strap covers are applies to increase comfort. Aesthetic appeal is incorporated into children's AFOs by the choice of designs available.

Peer perception or stigmatisation

Linked to the device and its visibility to others, peer perception was another concern that was raised across a number of papers. External assistive devices can be perceived by others as a symbol of disability, and the visibility of the device and concerns about how others reacted to it was mentioned by users in a number of papers (Garralda et la., 2006; Vinci & Gargulio, 2008; Hayles et al., 2015; Holtkamp et al., 2016; Swinnen et al., 2018a; Swinnen et al., 2018b; Osam et al., 2019; Ireno al., 2019). This concern was expressed in a number of ways: some individuals described choosing not to wear their AFO during social situations because they felt uncomfortable looking different from their peers, others described wanting to conform and appear the same as their peer group but still wore the device, while others described experiencing stigmatisation, embarrassment, or not feeling welcome as a result of wearing an AFO. It was common for users to discuss how the device affected their appearance and self-image, and how it often conflicted with how they want to appear and the identity that they wanted to present.

Further research into the clothing choices of disabled students reinforced this conflict, and identified a willingness of people with disabilities to avoid clothing which acted as an identifier of their disability to their able-bodied peers (Kaiser, Freeman & Wingate, 1985), or a desire to find clothing which conceals assistive devices from peers and therefore removes the symbol of disability (Stokes & Black, 2012). The physical and social environment that the student lived in was also suggested to also have an impact on these factors (Stokes & Black, 2012). With the additional difficulties of developing identity and social environmental flux, childhood and adolescence represent a significant age range that may be influenced by external pressures into being reluctant to wear AFOs, and this is regularly mentioned in the literature; as expressed by a parent in an interview about their child's AFO usage: "*we have a 13-year-old who just wants to be like other 13-year-old girls, and she doesn't want to wear AFOs…*" (Hayles et al., 2015). While there is limited work that can be done to improve this, research indicates that improving perception of the device and user empowerment can improve compliance rates (Desmond & McLachlan, 2002).

Personal elements

Although a much harder factor to investigate, there is some very weak evidence to support the effect that personal factors have on compliance levels. Demographic factors, e.g. gender, socio-economic status, or ethnicity/cultural factors, and the influence that they have over compliance are raised in the literature but with few conclusive results (Al-Jewair, Suri & Tompson, 2011; White, Bannerman & Gillett, 2016).

Age has already been established as a factor which is linked to compliance with under 18s exhibiting the poorest compliance rates (Wingstrand et al., 2014), while gender was reported to not be associated with differences in satisfaction levels regarding an orthotic device (Swinnen et al., 2018). There was some suggesting that suggestion that personality or psychological characteristics of users influencing their likelihood to comply with AFO direction or not (Sugawara et al., 2018), while increased confidence as a result of wearing the AFO was also suggested to be likely to influence willingness to comply (Swinnen et al., 2018).

Support from family and friends

The influence of other people such as family and friends is also mentioned in the literature as a factor which can affect AFO usage, strong relationships and emotional support from close peers has been shown to positively impact on the compliance rates of adolescents (Al-Jewair, Suri, & Tompson, 2011; White, Bannerman, & Gillett, 2016). Parents in particular, can have a great influence on their children. A number of studies discussed the effect that parents' perception of AFOs can have on their child's usage levels finding that where parents have a positive perception of the device and perceive it to benefit their child's ability and independence, they were more likely to encourage their child to use it as directed (Naslund et al., 2003; Ghoseiri & Bahramian, 2011; Hayles, Harvey, Pummer & Jones, 2015). Though it is likely that the participation groups for these studies is likely to biased towards parents who are more research minded or invested in the orthosis and supporting their child, and this may have influenced the results.

Psychological responses

Many papers suggested psychological influences linked with compliance. On a very simple level, patients who think that the prescription is necessary for them and think that it's important to wear the device are the patients who are most likely to wear their orthosis and comply with usage recommendations (Sugawara et al., 2018). Those who accept the recommended device and prescribed usage and are satisfied with the support are also likely to exhibit higher compliance (Molloy, Graham, McGuiness, 2012; White, Bannerman & Gillett, 2016; Eddison, 2018). However, there are also some additional theories which are suggested to be influential in a person’s decision to comply with clinical instruction.

The locus of control describes the extent to which people consider that they have control over events which occur in their external environments (Rotter, 1966). People sit on a spectrum ranging from having a high internal locus of control, where an individual may believe that they have complete control over external circumstances, to a high external locus of control, where they perceive that they have no control over external circumstances. A high internal locus of control has been discussed as being a factor which can positively influence compliance (White, Bannerman & Gillett, 2016; Molloy, Graham, McGuiness, 2012); those who perceive that they can control or contribute to their experiences are more likely to take greater responsibility for their condition and engage with behaviours which have been recommended by their clinicians.

Anticipated regret is also reported to impact on patient compliance. Anticipated regret describes patients who expect to regret or experience other negative emotions as a result of a future action or choice, and where an individual has a low intention to comply, and a high anticipated regret, compliance will be low. Patients who believe that using an AFO, or complying with medical advice, will not produce the effect that they feel they need, or will lead to negative social or physical outcomes, are less likely to comply with the recommended use (Molloy, Graham, McGuiness, 2012). A similar interaction occurs between expectation and experience. Where the patient’s expectation of an assistive device is greater than the experience that they have when they use it, they are likely to abandon the device or not use it very often. Where expectation and experience are similar, or experience exceeds expectations, assistive devices are reported to show increased use (van Netten et al., 2010; Schwarze et al., 2019).

Medical relationships

The relationship that a patient has with their clinical staff has also been suggested to impact on the extent that they comply with the recommended usage (Al-Jewair, Suri & Tompson, 2011). Most commonly mentioned was the importance of patient confidence in the prescription and the clinicians (Muscari, 1998; White, Bannerman & Gillett, 2016), but patient understanding of the clinician's recommendation is also suggested to influence rates of compliance (White, Bannerman & Gillett, 2016).

Cost

Any cost associated with the device or accessing the clinic has been reported to be a potential impactor on a patient's likelihood to comply with a prescription (Muscari, 1998; Chan et al., 2014; Ghoseiri & Bahramian, 2011; White, Bannerman & GIllet, 2016; Osam et al., 2019), affecting patients with a lower socio-economic status most. In the UK this is mediated by the NHS so patients do not need to pay for their AFO or the assessment times, but the cost of travelling to the clinic for follow up visits or the loss of money associated with having to take time off work could potentially affect compliance, or patients' ability to participate in research studies.

Inconvenience to the user

Inconvenience, or the burden that the prescribed intervention poses to the patient, has been described as a considerable factor in influencing patient compliance. The complexity of the prescription, any concerns that patients have about the device, the amount of change that the patient has to undergo in order to incorporate the device into their routine, or the duration that the intervention has to be carried out for, have all been identified as elements which affect individual's likelihood to engage with clinicians' recommendations (Muscari, 1998; Molloy, Graham, & McGuiness, 2002; Maas et al., 2014). This is reflected in compliance rates of people who have had assistive devices for varying amounts of time. Where a patient is new to using an assistive device, compliance is more likely to be poor, whereas where a patient has had a device, or a number of devices in the past, they are more likely to show higher usage habits (Djicks et al., 2006). Regular rehab sessions, or clinic visits, has been described as a method which improves usage because the visit reminds the patient to engage with the device and encourages them to develop habits, reducing the perception of inconvenience long term (Sugawara et al., 2018).

Device redundancy

One of the most uncontrollable factors which may be reflected in compliance levels is simply linked to change over time; cases where the device becomes redundant. This could be because the device becomes unsuitable over time due to worsening or improvement of the condition, perhaps linked with recent surgery, or it could be because it is more appropriate, contextually, to use a different device (Phillips & Zhao, 1993; Ghoseiri & Bahramian, 2011;

Basaran et al., 2016; Sugawara et al., 2018). A lack of use of a device over time does not necessarily constitute a lack of compliance.

3.7 Conclusion

Healthcare, particularly healthcare of visible conditions, or where medical devices are noticeably visible to peers, occupies not only a medical field but is intertwined with sociological and psychological factors (Luger, Geiger & Lyner-Cleophas, 2019), and this complicates a patient's choice to comply with clinical recommendation. AFOs in particular, as a medical device which is worn externally and which is visible to peers bridges these field, and this is reflected in the wide range of factors which influence patients' decisions to use them. These findings also emphasise the wide variety of subjective experiences surrounding impairment for both affected children and their families (Cohen, Biran, Aran & Gross-Tsur, 2008). It is apparent that, like the varied usage patterns between individuals, there is no unanimous opinion regarding AFOs and where they're worn (Swinnen et al., 2018b).

Lack of consideration of user opinion in AFO development and selection process is already an established finding in the literature (Phillips and Zhao, 1993) and one which can have a big impact on the extent that the device is worn. There is an increasing recognition of the agency which the user holds in deciding whether or not they will wear the device (Holtkamp et al., 2016), and so the need for the clinician to work with the patient to determine the factors that influence their usage in order to ensure maximum usage time. Further work can always be done to improve understanding of factors which influence compliance and into methods which can be used to predict and encourage compliance in younger patients (Windebank & Spinetta, 2008) but in order for this to be effective, these findings emphasise the need to discuss these factors with each AFO user individually, in order to find out more about the environments that they will be wearing the AFO in, any barriers, and what actions might support and encourage them to use their AFO (Windebank & Spinetta, 2008; Holtkamp et al., 2016).

Working holistically to view all aspects of the patient and their social environment is important to be able to understand the impact that the AFO has on them (Eddison, 2018) and hopefully work with them to develop strategies which will encourage long term use and bring the associated benefits. With such a great number of factors which could influence an individual's commitment to wearing an AFO, to greater or lesser degrees, communication with them about what will help improve their usage is essential. There is already evidence to support the suggestion that if an AFO is adapted to meet the needs of the child, it can improve the adherence (Van der Wilk, Hijmans, Postema, Verkerke, 2017). Targeting research to develop interventions and investigations which work with patients to encourage them to wear their assistive devices and allows them to discuss the reasons why they do and do not wear their devices, rather than simply recommending wear time, would ensure that the patient was supported in their usage of assistive devices and would hopefully impact on their compliance overall.

Compliance interventions

There are a number of interventions which have been trialled to improve compliance in clinical settings, some of which feature virtual communication as a focal point, increasing the level of contact that patients receive with healthcare professionals at minimum cost to those involved. Windebank & Spinetta (2008) advocated a development of a range of forms of communication for patients, with calls for accessible information to be made available to patients and increased contact with patients between clinic visits, for example through emails, phone calls or in-person visits. A recent intervention engaged these principles and gave a group of young adults access to an internet-based health information program where they were able to access information and support for a range of lifestyle and welfare topics (Coşkun, Güvenç, Bebiş, 2019). After three months this group were compared to a control group and they showed significant improvements in health promotion behaviours and e-health literacy, education which was likely to promote positive lifestyle choices in the future.

A recent paper which investigated post-orthodontic retainer use in young people carried out a pilot study using WhatsApp chat groups moderated by orthodontists to encourage retainer use (Zotti et al., 2019). Patients were encouraged to send weekly snapshots which were then assessed by the orthodontist and a top five was established at the end of the month. The intervention was successful and the regular contact with patients was reported to increase compliance rates with the retainer and attendance at check-up appointments which led to a better dental outcome compared to a control group. A similar study which sent out weekly text reminders to orthodontic clients about oral hygiene also reported that the contacted group exhibited better oral hygiene in check-up appointments compared to a control group who did not receive any text messages (Jejurikar et al., 2014).

These studies have positive implications for medical interventions and methods to improve patients' engagement with clinical recommendation and assistive devices. Patients who receive regular, accessible information from their clinic and who have an accessible means of communication with medical professionals appear to show increased compliance and engagement with behaviours which are beneficial for health and wellbeing. A development of a similar strategy for AFO users could well impact on poor usage levels.

Chapter Four - Methodologies

4.1 Introduction

This project seeks to understand the factors which affect the wellbeing of children and young adults with CP and which impact the acceptance and usage of AFOs. This will be carried out in four key stages using mixed methodologies to investigate the subject thoroughly:

A. Measurement of the functional effect of AFOs on the gait of children with CP through the use of 3D motion capture and biomechanical assessment of gait.

B. Monitoring of the everyday usage of AFOs by children with CP using temperature measurement over a period of three months.

C. Interviews with children with CP who use AFOs to explore their experiences and perceptions of their AFOs.

D. Focus groups with able-bodied children in mainstream schools of a similar age to the participants recruited for the former three points, to determine their perceptions of AFOs and children with CP.

These will functionally be divided into two groups, with the 3D motion capture (A), compliance monitoring (B), and interviews with patients (C) being carried out as case studies on one group of four participants, and a separate group of children being recruited for the focus groups (D). The case studies will allow for a detailed analysis of the factors which influence individual levels of compliance, while the mainstream class members represent the peer groups of the initial participants, and provide contextual data for a holistic assessment of the elements which influence compliance. The combination of methods and target participants should allow for a detailed assessment of the relationship that children with CP have with their AFOs: both the degree that they wear them, and the factors which influence this usage. Although these factors will all be individual to the recruited participants, they will provide valuable insight into the kinds of factors which may be impacting on similar AFO users and will allow clinicians to consider these elements in the future.

It is important to note that these studies were not carried out. The onset of the Covid-19 pandemic cancelled all schools and non-essential research in hospitals (discussed in more detail in later chapters), forcing this project to be put on hold.

4.2 Ethical considerations

Ethical approval was obtained for all parts of this project prior to recruitment. Approval for the case studies: 3D movement analysis, compliance measurement, and the interviews, which involved clinical patients, were all sought and granted from the Integrated Research Application System (IRAS) (Application reference: 265723, see Appendix 1). Favourable ethical opinion for the non-clinical school focus groups was granted by Keele University Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS REC) (Application reference: MH-190066, see Appendix 2).

All participating children and their parents will be given written information sheets and assent/consent forms (Appendix 3) to discuss and consider in private prior to agreeing to participate with the study. Signed assent and consent forms will both be required for any child to take part to ensure that both parties are happy for the child to take part. No deception will take place for any of the research elements, participants will be fully informed about the study prior to declaring their consent/assent. All children and parents will be made aware of the voluntary nature of the study and will be informed that they can leave the sessions or withdraw their data at any point without any repercussions or disappointment.

No participants will be recruited directly by the researcher but instead will be contacted through a mediating party. In the case of the hospital patients, a clinician will carry out the initial recruitment and in the case of the school pupils, the researcher will contact the headteacher for further support in recruiting. For the safety and welfare of all involved, the researcher will never be left alone with any of the participants and has undergone a DBS check prior to engaging with the research.

The data collected for the project will be stored according to GDPR requirements and in line with Keele Data Management Policies. All data will be anonymised and stored confidentially and securely on a password-protected, university laptop.

4.3 Clinical studies (Studies A, B, and C)

All data collection elements for studies A and C, and the fitting appointments for study B will take place in the partner clinic.

4.3.i Participants

Four patients (two males, two females; aged 9-13) with CP and who use AFOs to assist their walking will be recruited for the patient-based aspects of the study. Participants have to be GMFCS level 1 or 2, have to be in mainstream education (one male and female from primary school, the others from secondary school) and will have to be using solid polypropylene AFOs to allow the usage sensor to be integrated into their device.

All participants will be recruited through the partner clinic. Potential participants who meet the inclusion criteria will initially be contacted by a clinician who will tell them briefly about the project and invite them to consider taking part. Information sheets and consent forms, both for the parents and the children, will be sent to them to help inform their decision (see Appendix 4) but they will be asked not to sign prior to the initial meeting with the researcher. If participants are happy to proceed, they will be invited to the clinic to meet the researcher and clinical supervisor. The project will be explained, and both the parents and children will have opportunities to ask questions before they sign the consent form. Both consent and assent must be given for the participant to take part in the study.

Inclusion criteria

The inclusion criteria for the participants will be as follows. They have to be:

- Children with cerebral palsy (spastic diplegia or hemiplegia)
- In mainstream education in years 5-6 (n=2) and 7-9 (n=2)
- Undergoing routine clinical management at RJAH Orthopaedic Hospital or its satellite clinics
- Using unilateral or bilateral moulded AFOs
- Able to walk independently (GMFCS level 1 or 2)
- Able to comply with experimental protocols.

Exclusion criteria

The exclusion criteria for the participants will be as follows. Participants cannot have:

- Any behavioural or communication problems which would make them unable to comply with the protocol
- Or have had invasive procedures (eg surgery, Botulinum toxin injections) in the previous 6 months
- Or be planned to undergo invasive procedures (eg surgery, Botulinum toxin injections) in the next 6 months.

Sample size justification

It is acknowledged that the sample size for this study is low. Ideally a much greater number of patients would be included as participants, however, given the time frame of the study, the small size of the research team, and the number of activities that each participant was required to do to take part, it was decided that four case studies would be sufficient for this study.

4.3.ii Equipment and procedure

Study A - 3D Motion capture and biomechanical assessment of patient walking

3D motion capture will be used to determine the kinetic and kinematic effects that wearing AFOs has on the participant's gait. Participants will be asked to attend a single 3D motion capture session where they will be assessed walking with and without their AFO.

3D motion capture is a service regularly provided by the orthopaedic clinic which this project was linked with to assess the gait of patients, particularly those with CP. It involves monitoring points on an individual's legs both when they are standing and while they are walking using both video and 3D tracking cameras (VICON, Oxford Metrics Ltd., Oxford, UK) to accurately measure how the patient walks. This data will then be used to calculate how the bones and muscles engage to produce the patient's gait (kinematics) and will be combined with data collected from force plates in the clinic floor, which calculates the forces and moments applied to the limbs. From these calculations, graphs will be produced to compare the patient's data to a calculated range of averages, and this will allow the specialists to identify any anomalies or differences which contribute to abnormal gait or any problematic areas. An analysis and comparison of the child's walking with and without their AFO will be used to determine the extent that the AFO affects the patient's gait and supports the user.

All measurements in this part of the study will be taken by trained professionals and data will be stored securely on the hospital servers. All elements of this part of the study are common practice in the clinic and as such, detailed guidelines and procedures are already available to ensure the process is carried out correctly and that participants are kept safe while they take part in the study. The process itself is non-invasive and very low risk to the patient and so is not predicted to cause any distress.

Study B – Measurement of usage

Usage of the AFO will be monitored to determine the extent that the participants comply with the directions of their clinicians.

Usage will be measured using an Orthotimer (Roller, 2020), a small sensor (9 x 13 x 4.5mm) which monitors usage of a device by taking the temperature at regular intervals. Specifically designed for orthotics and assistive devices, the Orthotimer and associated equipment are described as being CE Class 1 (MDD 2007/47 /CE) and FDA approved for the purposes of medical use. Sensors are waterproof and dust proof, ensuring that the children are able to carry out their normal behaviour without risk to the device or the data.

The Orthotimer software complies with GDPR regulations and will never be linked to any personal data, ensuring that patients' data will remain secure throughout the course of the project. The sensors can only be read by the equipment which initiated their recording ensuring that no-one other than those on the project can look at the data.

Orthotimers will be fitted to the AFOs by the department technician using a specifically produced tool. The AFOs will be moulded to incorporate the sensor at the back of the leg between the upper straps and the Orthotimer will be placed on the inside of the device so that the face of the sensor will lie flat against the user's leg; flush with the contacting plastic of the AFO to reduce pinching or sores. Given that the Schwarze et al. study (2019) had reported problems with the data recovery and technical issues with the devices, two sensors will be fitted per child, one on each of the child's AFOs, in the hope that the combination of the two data sets will ensure a complete data set per child. Children will be told to come back for further adjustment if the AFO caused any problems or discomfort.

The sensors will be fitted when the participants come to the hospital to undertake their 3D motion capture and will be programmed to log the temperature at 15 minute intervals over a three month period. All participants will be made aware of the sensors and the data that they will be collecting prior to fitting, though they will not be informed about the mechanism that the sensor uses to collect data, to reduce temptation to manipulate the results. Participants will also be reassured that there will be no repercussions for non-compliance or only partial compliance and that their usage will not be shared with any of the clinicians who are handling their care.

When the patients return to the clinic after three months, data stored on the sensor will be recovered and the sensors will be removed. As recommended by the manufacturer, wearing time was described as time where the values were reported between 29 and 38.5°C (Roller, 2020). The data will then be used to calculate the percentage of time that the participants wore their AFO compared with the wearing time that was recommended by the clinician.

Study C – Interviews with patients

Semi-structured interviews will be carried out with the participants to explore their perceptions and experiences of AFOs and to see what factors affect their willingness to use them. Interviews will be made up of a series of predefined questions but will be flexible in order to incorporate the interests and needs of the child (see Appendix 5 for the interview schedule) and will be carried out between just the researcher and the participant. Interviews will be allocated for an hour but will be flexible to meet the needs and energy levels of the participants.

Due to the age of the patients who are being interviewed, standard interview techniques have been adapted to make the discussion more engaging and encourage the children to discuss anything relevant to the project. In addition to the interview questions, a worksheet has been devised for the discussion and a series of stickers produced, to act as an adapted emotion mapping technique (Gabb & Singh, 2015) and way to stimulate discussion (see Appendix 6). These worksheets and stickers will be used to support the child's answer, but also minimise stress and increase engagement with the interview. The map has been designed to be engaging and easy to make specific for the participant. The stickers (Appendix 7) were based on emojis, selected for their accessibility but ambiguity of meaning so that the child has to explain their choices to the interviewer. AFO specific stickers (Appendix 8) have also been produced to record the locations where AFOs were worn.

The interviews will be hosted within the hospital, ensuring a safe, familiar location for both parties. The interview questions have been devised so as to avoid any undue distress, although it is acknowledged that, due to the nature of the topic, distressing topics may arise as part of discussion. Children will not be forced to discuss any topics and will be made aware of their ability to pause or stop the interview at any point. In order to safeguard participating children's welfare, parents will be asked to sit in during the interview so that they can monitor the discussion, though they will be asked not to engage verbally so that they do not affect the child's comments. All data will be stored securely on the hospital servers.

The interviews will be video recorded to reduce the amount of notes that the interviewer had to take while talking to the participant; consent will be given for this by both the parent and child prior to the interview taking place. These will then be transcribed by the researcher to produce a verbatim transcript of the interview.

Parents

Research suggests that there are often discrepancies between the views and opinions of parents and children (Schiariti et al, 2014). As AFO users have first-hand experience of living with CP and an AFO, they are best placed to describe their experiences and the factors which influence their compliance, as such, their views will be prioritised in the data collection for study. However, in the interest of the safety and welfare of both the participant and the researcher, the parents will be asked to remain in the room while the interview took place. To avoid parents contributing during the interview and potentially influencing what the child may say about their experiences, they will be seated to the side in the room and will be given tasks to complete during the time (see Appendix 9). The information sheet for the task will also include a comment asking them to refrain from commenting verbally during the interview but will invite them to complete the same tasks as the child and encourage them to add comment or elaborate on their child's comments on paper.

Although priority will be given to the data produced by the child, the additional information from the parents will provide, further perspectives and insight, and will be used to support the findings from the participant's interview.

4.4 Non-clinical study (D)

4.4.i Participants and recruitment

Two groups of eight participants will take part in a focus group designed to explore unimpaired children's perceptions of people with pathological gait patterns and assistive devices. The first focus group will be made up of participants from primary school years five to six (aged between 9 and 11 years), while the second will be made of up of participants from secondary school years seven to eight (aged between 11 and 13). Focus groups will be conducted in primary and secondary schools in Stoke on Trent, using existing contacts made by the researcher and the School of Health and Rehabilitation at Keele University. Where possible participant selection will ensure a diverse range of participants who represent the demographics of the participating school.

Children who have cerebral palsy or mobility problems, or those with close family members with cerebral palsy or who use assistive devices to help them walk, will be excluded from the recruitment to ensure that the data collected reflects the opinions of unimpaired children who have little to no experience of AFOs or children with CP, but also to avoid potential distress to participants.

Recruitment will take place indirectly through the school. The headteacher of the school will initially be contacted to briefly describe the project and determine willingness to participate, see Appendix 11 for opening letter to the school. Following a prospective agreement, a second email will be sent with full details of the study and the requirements of participation for the school, see Appendix 12. Following the headteacher agreeing to the school's participation, arrangements will be made to allow the researcher to meet with potential participants and their parents to discuss the project and what their participation will entail. At all points, the teaching staff of the school will act as the mediating party for the researcher and provide access to prospective participants, rather than the researcher contacting the children directly. Prospective participants will be given information sheets, and consent and assent forms and will be told to take them home for further discussion within their family. A minimum of 24 hours will be given to prospective participants to consider taking part in the study before they will be able to return their forms, and families will be able to ask any additional questions about the study via email before they agree to take part. Willing participants will require both consent and assent forms to take part. The voluntary nature of the study and ability of the child to withdraw without reason will be emphasised at all points in the recruitment stage.

4.4.ii Equipment and procedures

A PowerPoint presentation and series of activities have been developed to guide the focus group in exploring the opinions of unimpaired children's perceptions of children with pathological gait patterns and assistive devices, see Appendix 13 for the focus group plan, questions, and presentation. Sessions have been designed to fit within an hour and include a number of engaging stimuli to attempt to maintain high levels of concentration and reduce attention fatigue amongst the participating children (Yuen, 2004; Krueger, 2014). These stimuli further act to enable the participants in their discussion. It is assumed that the children will have had limited experience with children with pathological gait patterns or assistive devices, so the questions and stimuli have been developed to provide the participants with a vocabulary that they can use in their analyses, and a visual understanding of the significant aspects of pathological gait treatment. Stimuli for this focus group include: an adapted warm up technique from theatre workshops (which will also help to reduce inhibitions linked to the video recording), video clips of pathological gait patterns, physical AFOs which can be handled and experienced, and sticker-based worksheets; all activities have been designed to allow the children to consider their own opinions and discuss these constructively as a group.

Participation and welfare

The focus group session will be hosted in the participating school which is both a safe location for both the participants and the moderator, and which will be comfortable and familiar for the children (Powell et al., 1996). The questions devised for the focus groups have been designed to be non-threatening and open-ended to minimise distress to the participants and to encourage discussion within the group. In order to further safeguard the participating children's welfare, a member of staff from the school will be asked to sit in on the session.

At the beginning of the session, all participants will be reminded of their ability to withdraw from the study either during or after the event without any question or repercussion. To make this easier for the children, every participant will be given a yellow card to sit on the desk in front of them (Hoban et al., 2017). Children will be told that if they want to leave at any point, they only have to hold up the yellow card and they will be able to leave without drawing the attention of the moderator or disrupting the conversation.

Moderation

These focus groups will be moderated by the researcher, no strategies will be engaged to mould the group response and the participants will be free to answer the questions in any order and to contribute as many times as they like. Care will be taken to ensure that individuals do not dominate the group, and that everyone is able to express their opinions without judgement. While many papers advise against the moderator and researcher being the same person (Powell et al., 1996), the size of this project meant that it is most appropriate for the researcher to take on this role themself. Care will be taken while moderating to facilitate rather than lead the discussion, and the whole focus group will be video and audio recorded to remove the need to take notes during the session. Following the session, the video will be used to produce a transcript of the event which will then be used for analysis.

4.4.iii Confidentiality

To maintain confidentiality, participating children will be told not to discuss the focus group with anyone outside of the group with the exception of their teachers and parents, who have been made exempt in the interest of the participants' safety and welfare.

4.5 Data analysis plan

Due to the mixed methods of data collection, a number of different analyses were carried out on the data:

Study A

The gait assessment data from the 3D motion capture will be analysed to assess the kinetic and kinematic differences between the patient's gait with and without their AFO.

Study B

The patient compliance data will be compared to the clinician's recommended usage to examine any differences.

Study C & D

Phenomenological analyses (Smith, Flowers & Larkin, 2009) will be carried out on both the interview and focus group data.

4.6 Researcher's epistemology

In recognition of the potential influence that presuppositions may have on the analyses of the data, and to minimise the impact that personal experience may have over the analysis, the researcher prospectively recorded her preconceptions, former experiences, and any potentially influencing thoughts and opinions at the beginning of the project (Appendix 14). This process allowed her to identify areas that might affect the analysis so that they could be considered and minimised in the later stages of the study.

Chapter Five: An assessment of the suitability of the Orthotimer as a sensor for the measurement of AFO compliance: A pilot study

5.1 Aim of the study

The Orthotimer, used in the study by Schwarze et al., (2019) is a specific sensor developed to measure orthotic compliance in a clinical setting (Roller, 2020). The literature surrounding measurement of compliance suggests that using temperature sensors is a valid method to measure usage of an assistive device (see Chapter Three), but there are some concerns about this particular sensor due to the significant amounts of data which was reported as corrupted or missing in the study by Schwarze et al., (2019). A pilot study was carried out to assess the suitability of the Orthotimer as the sensor for the measurement of compliance in this study.

The following aims were determined for this project:

- To determine whether the Orthotimer is an appropriate sensor to measure AFO compliance.
- To confirm that the developed sensor fitting technique allows the sensor to adequately detect orthosis usage through temperature measurement.
- To identify any problems with the process of collecting compliance data so that adaptive measures can be developed before integrating the sensor into clinical practice.

5.2 Clinical Relevance

A successful compliance monitor will allow clinicians to determine the usage of assistive devices which will support their clinical decision making. The Orthotimer is currently being considered as a method for measuring AFO usage in patients by the hospital department linked with this study. This pilot study will provide useful insight into the viability of using these sensors with patients, confirm the best method to fit them to patients’ AFOs, and will identify any problems so that they can be considered before integration into future clinical practice.

5.3 Methods

The researcher undertook this pilot study individually prior to beginning the participant trials. An AFO was adapted to enable it to be worn on the arm by the researcher for the duration of the study (see Image 2), the Orthotimer was fitted to the adapted AFO as was proposed for the participant AFOs: with the sensor impressed between the strap connections so that it was held against the skin when the AFO was worn.

Image 3: The adapted AFO (Stewart, 2020)

The researcher manually recorded the hours of wear over 14 days. At the end of the study, the data from the Orthotimer was collected using the Orthotimer equipment and software. An assessment of the quality of the data report was then made by comparing the manually recorded wear time with the Orthotimer recorded wear time.

5.4 Results

Attempts to remove the data from the sensor failed due to problems with the device and software. No results were obtained for this study.

5.5 Discussion

The opportunity to practice fitting the Orthotimer to the AFO and the chance to test the fit for comfort to participants was invaluable to this study. The process was carried out effectively and no discomfort was experienced by the researcher as a result of the integrated sensor. These practices will be continued in the wider study.

While the results from this experiment were absent, the study has been useful as a learning experience. The difficulties exhibited in trying to remove the data from this sensor were similar to the records of data loss and corruption experienced by Schwartz and colleagues (2019). Given that this study has also experienced data loss, it has highlighted the need to incorporate more than one device per participant into the study design so as to minimise the chances of data loss following the observational period. Further investigation into similar temperature-based sensors may also be beneficial to see if there is a similar make which reports lower levels of data loss and which could be used instead of the Orthotimer in future projects.

Chapter Six: The transition: Explanation of project change in context of Covid-19 and lockdown

The Covid-19 pandemic has dominated 2020. Originating in the final days of 2019, the virus was officially classed as a pandemic on the 11th March 2020 with more than 116,000 people infected worldwide. These numbers grew over the following months affecting jobs, families, stock markets, the economy, and the way of life of everyone across the world. In the UK, measures to reduce the spread of the virus were implemented, and on the 23rd March, with over 6,000 people infected with the virus, Britain went into lockdown. The working and family arrangements for many across the country changed overnight. Places of work including schools and universities closed, and the NHS underwent significant changes to their services though the extent of these changes varied between hospitals. As part of these developments, which will be discussed in greater detail in Chapter Seven, the NHS placed restrictions on carrying out non-essential research, restricting the completion of the former study, and so a new study was developed to make up the remainder of the thesis.

Covid-19 and the events which have occurred to try and mitigate the impact of the pandemic have led to a country full of uncertainty about the present and future (Bailey & West, 2020). It is in this crisis and uncertainty that the following elements of the project are situated. As the UK begins its second national lockdown (5th November), it is evident that the virus is an ongoing problem that will continue to affect the country into at least the following year, and that there will continue to be long-term effects beyond the physical threat of the virus itself. In recognition of the pressure and psychological stress that many are facing due to the pandemic (McMullan et al., 2020), a recent Lancet paper emphasised the need for research into the social and psychological impacts of the Covid-19 pandemic on those who provide care to vulnerable people (Holmes et al., 2020). The following study answers this call and investigates the social and psychological impact of rapidly implemented changes to policy and practice on staff working in an NHS Trust during the pandemic.

Part Two: Investigating the experiences of healthcare staff during the Covid-19 pandemic

Chapter Seven: Introduction: Identity and boundaries during times of crisis and Covid-19

7.1 Introduction

In the current climate, the taken for granted way of living has changed dramatically for most people. Lockdown saw the population limited to their houses with few opportunities to leave, and employees who were not defined as key workers were required to work from home or were put on furlough. These measures worked to reduce the infection rate of the virus but did not fully consider the consequences on the individuals subjected to the changes. This chapter will consider the effect that crises, like the Covid-19 pandemic, and the changes implemented in organisations as a result of the emergency, can have on individuals' identity and work practices by focusing on the making and remaking of boundaries between social groups within an NHS Trust.

This chapter will introduce the literature surrounding identity, crises and liminality. It will start by discussing identity, particularly relational, social and personal, with a focus on how an individual's identity changes, is maintained, and is expressed. Following this will be discussion about crises and wicked problems, and liminality, with observations about how they apply to Covid-19, before a discussion about how Covid-19 has affected the NHS and catalysed organisational change. Finally, the chapter is rounded off with a reflection of the impact of organisational change on both identity and boundaries between social groups, and then moves on to present the aims and methodologies for this study.

7.2 Identity

Identity is a psychologically complex, multi-faceted internal construction of the self which reflects the experiences and inner thoughts of an individual and affects how they behave (Karreman & Alvesson, 2001; Ybema, 2010; Miscenko & Day, 2016). A common theory is that people's identities are insecure, that they are constantly readjusting and revising, changing according to situation, relationship with peers, and memories (Ibarra & Barbulescu, 2010; Fraher & Gabriel, 2014; Hoyer & Steyaert, 2015) though others suggest that an individual's identity is established and consolidated over time, reinforced with many years of experiences (Hoyer & Steyaert, 2015). However, both theories agree that: identity is dynamic and constantly updating, being constructed from an individual's remembered past and perceived future (Ybema, 2010), and impacted to some degree by every experience and interaction that people undertake in all of the environments that they inhabit (Daskalaki, Butler, Petrovic, 2016; Ashforth et al., 2018; Brown, 2019).

Identity is multidimensional, built up of many facets or subidentities which are developed in response to the daily experiences of the individual and the people who they interact with (Miscenko & Day, 2016). In general, it is suggested that people constantly carry out internal cognitive work to produce a stable identity which is harmonious with the environment it acts within (Zheng, Meister, & Caza, 2020). This cognitive work is the basis of subidentities, which are facets of an individual which present as their identity in a specific scenario, adjusting presentation or dominance of the various facets according to the circumstances at hand. These subidentities may be quite different, for example the identity presented during work is likely to be very different from the identity exhibited when spending time with children, but the subdivision of identity in this way enables greater identity fluidity between different environments (Miscenko & Day, 2016; Brown, 2019). Problems can arise where these facets and subidentities conflict or contradict each other in a particular circumstance, for example a group identity which is required to incorporate an idea contrary to a personal belief, and this conflict can initiate negative emotions and identity problems within the individual (Petriglieri, 2011), also inciting further identity work following the event to reconcile the conflict (Ybema, 2010).

There are a number of different aspects of identity, but the most relevant to this project are: relational, social, and personal (Brown, 2019; Frick & Brodin, 2020). These elements are intertwined, constantly developing, interacting, and adjusting their presentation according to the different situations individuals are placed in, and shaping how people present and identify themselves (Stets & Burke, 2000; Karreman & Alvesson, 2001). Relational (or role) identity revolves around the roles that people hold or enact, particularly within a working environment, and how people change their behaviour and interact within those roles (Sluss & Ashforth, 2007; Ibarra et al., 2010). These identities directly pertain to the relationships and interactions between people and the roles which the people involved are acting within, and acknowledges that one role cannot exist without the network that it functions within, for example it is not possible to be a manager if there are no employees to manage (Sluss & Ashforth, 2007; Frick & Brodin, 2020). Social identity is constructed in relation to group memberships and is developed through the identification with in-groups and the rejection of values associated with out-groups (Tajfel & Turner, 1986). This often results in identity construction associated with depersonalisation, as individuals align with each other and share opinions, ideals, and symbols to denote belonging with a particular group rather than considering personal views or stances (Sluss & Ashforth, 2007). Personal identity describes the facets of identity which are built from personal experiences, perceptions, and opinions, independent of other people or group membership. While personal identity is unique and intrinsically produced, it can be shaped by other people and the circumstances which people are exposed to (Frick & Brodin, 2020). An individual's work identity (the person they present as during their working hours) is constructed from personal identity traits and reactions to events; relational identity from the career role; and the social identity they gain as part of the workforce (Miscenko & Day, 2016). All of these facets interact and affect each other: just as each individual has their relational and social identity affected by their workplace and their personal identity, their workplace identities and the relationships and experiences they have in that environment feed back into their personal identity; none exist in isolation but rely on the others to develop (Miscenko & Day, 2016).

Identity development is most keenly established and maintained through use of language, both in internal storytelling and in conversation with others (Boussebaa & Brown, 2017) though there have been records of non-linguistic features being used as part of identity development (Brown, 2019), for example the symbolic use of particular hair styles or accessories. One of the most prevalent forms of linguistic identity development is through the use of stories and storytelling, and it has been suggested that the narratives that people use to describe their past and present are not necessarily a description of their reality but a representation of how the speaker's perceives and understands the world and therefore represent a facet of their identity. The narrative identity theory discusses how people construct their lives and relationships with others through telling and retelling stories (Benwell & Stokoe, 2010). It is through this storytelling method of remembering and processing that people experience their life, make sense of the circumstances in relation to their history, instil meaning, and shape their identities (Stokoe & Edwards, 2006). Telling stories about people or past experiences, even daily discussion, helps to build and maintain a consistent identity, shape present identity, and share that with others (Alvesson & Kärreman, 2007). Narrative expression and individual identities therefore represent a means to investigate the experiences and perceptions of individuals. Diary entries describe and construct the understanding of the individual and their past as they perceived and remember it. Pursuing their memories offers an opportunity to understand the aspects which make up and influence their identity and the underlying messages that they use to support their existence and behaviour (Shamir & Eilam, 2005), and this can be used organisationally to understand the effects of organisational changes.

As identity is dynamic and constantly adapts to changes in an individual's circumstances, it is constantly affected by the events which individuals' experience in their daily lives. Significant events like crises therefore not only physically impact on people but can cause internal strife by catalysing reactionary identity work. Further discussion about crises features in greater detail below.

7.3 Crises, wicked problems, and liminality

7.3.i. Crises

A crisis is an unexpected event or period of time which significantly threatens a former way of life (Kornberger, Leixnering & Meyer, 2019), a situation where traditional values and rules are no longer circumstantially appropriate. It is a disorientating, transitory period of time which divides history into a before and after phase, disconnected from the past because the traditions and laws have been lost and alienated from the previously conceived futures which become impossible in light of the new present. Covid-19, having dramatically changed the way of lives of everyone on the planet, represents a significant current global health crisis (Kornberger, Leixnering & Meyer, 2019; Nembhard et al., 2020).

A key element of crises is the time pressure applied to the situation. In crises, decisions and actions need to be made decisively and rapidly to address the situation at hand, though leadership figures also need to be flexible in order to respond to new information or problems as circumstances demand (Kornberger, Leixnering & Meyer, 2019). These decisions are generally made by public authority figures who expect to have to work authoritatively and issue strict rules and regulations (Heide, 2004), and plans are produced in a drip feed fashion with constant prioritisation and assessments taking place to guide the decision making (Kornberger, Leixnering, Meyer, 2019). However, figures of authority cannot effectively contribute to processing and dealing with the crisis situation alone. In a crisis situation, it is essential that the public engage with the measures implemented to attempt to reduce the impact of the problem on an individual level. If the public refuses to carry out the actions proposed by the government, the measures will be ineffective (Klasche, 2020; Moon, 2020). Effective decision making during a crisis requires two key elements to be utilised and integrated into tackling the problem, and the ability to be able to move fluidly between the two. Decisions have to be made quickly and flexibly in response to upcoming information, but also carefully and with a strong sense of direction. Those who are working to make decisions need to be able to move dynamically between the two at all points with a delicate balance between thought and action moving beyond choices anchored in past conceptions and ideals (Kornberger, Leixnering & Meyer, 2019). Decentralised decision making, which specifically addresses the needs of individuals or workplaces allows for the most rapid decision making to occur and it is in this situation that decisions are most able to immediately meet the needs of situation as it occurs, effectively assessing and remedying the crisis situation (Kornberger, Leixnering & Meyer, 2019). Many of these decision making principles have been observed throughout the UK during the Covid-19 crisis. The government has been forced to make decisions quickly in response to new data and adapt as circumstances change, all the while working towards a greater aim of supporting the country through the crisis to a post-Covid phase. In particular, the country has seen the importance of the public engaging with the measures to collectively manage the problem, and how individual choices to not abide by the suggested regulations can cause setbacks across the nation.

The human response to crises varies between individuals, but it has been suggested that people in a crisis generally act through existential angst rather than fear (Kornberger, Lexinering & Meyer, 2019). Interestingly, despite regular predictions otherwise, it has been noted that individuals are generally quite rational in crisis situations and that many also go out of their way to help and support others without being mandated by figures of authority (Heide, 2004), something that was particularly present during the early phases of the pandemic. However, although people are likely to remain rational, the events and pressures associated with crises can impact those who live through them. Conflict and crisis can be instruments of change for identity. Crisis associated stresses such as not feeling in control, not feeling safe, absence of specific training/preparation for the circumstances, and poor leadership (Brooks et al., 2015) are common and act as a threat to personal identity and perceived external image (Ybema, 2010). People often experience additional struggle with these identity threats because of the other challenges they are already facing, and they often experience difficulties with gaining the support needed for these stresses, due to the external circumstances (Brooks et al., 2015). The result of these stresses is that people often undertake significant identity work to adapt to the situation they find themselves within as they try to maintain a positive personal identity (Ybema, 2010).

7.3.ii. Wicked problems

Wicked problems are crises that have not happened before, or that people are unaware of how to solve. They define a specific set of problems which are the antithesis to the every-day 'tame' problems which we tackle on a day to day basis. While tame problems describe the prototypical problem which has a clear solution, wicked problems are complex and are made up of multiple elements which interact and contribute to the problem, increasing the complexity and making them difficult to approach (Rittel & Webber, 1973; Grint, 2008). There are no simple right or wrong solutions to wicked problems; they are wicked problems because they can't be solved. The remedies are often complex and specialised to the problem at hand and make the situation better or worse rather than fixing the problem in a concrete manner (Head, 2019). For this reason, it is often suggested that the process of defining and understanding the problem is often a significant part of the solution (Rittel & Webber, 1973).

Wicked problems are common in areas like public policy where problems are widespread and affected by a number of factors, common examples in society include poverty and public health care. The Covid-19 pandemic, a global health crisis, could also be deemed to be a wicked problem because it is a crisis which has not occurred before. Specifically it is a crisis that revolves around a novel, highly-infectious virus of which there was no existing medical knowledge prior to the onset of the pandemic. Furthermore, to respond to the virus, countries had to adapt and develop measures to attempt to mitigate the impact of the virus. There was no simple solution to the pandemic, but a series of complex and interacting factors (e.g. unemployment, poverty, mental and emotional wellbeing) which further complicated the wicked problem of the pandemic and made it difficult to solve in a simple way. Wicked problems require engagement on a number of levels and a willingness of all individuals to work with the guidance to promote the proposed solutions and solve the problem. Due to the interaction between the contributing factors which make up each wicked problem and the potential impact that unforeseen consequences of actions can have on the public, there is often a time pressure on finding a way to improve the situation. There is often very little room for error in decision making as proposed actions to help cannot be tested beforehand and the full scale of the consequences of those actions are very difficult to predict before they are carried out (Rittel & Webber, 1973). A broad, holistic approach is therefore needed to approach wicked problems, in particular a collaborative effort that acknowledges the diversity of factors which influence the problem in question and which embraces the community in engaging a response (Grint, 2008). Multidisciplinary groups, with their wide range of backgrounds, offer a strong background and comprehension of the significance of interrelation which is then likely to achieve a long-lasting positive result than acting quickly to solve the most apparent facet of the problem.

Wicked problems and crises represent a period of change and transition that is unique from the past which leads up to it or the future that follows on afterwards. A time between where everyone is placed into a liminal experience and must consider their new position and it relates to their past and their perception of their future (Petriglieri, 2015). The lockdown period in particular, but also the wider Covid-19 pandemic represents a temporal liminal period, a period of limbo due to the crisis, which we hope one day to move out of and into a post-Covid era. This will be explored in greater detail in the following section.

7.3.iii. Liminality

Liminality describes ambiguous occurrences, temporal or spatial, which exist between two definite elements. Liminal situations are transitional and are distinct from the elements which surround it, defined by the absence of normative scripts and schemas which typically construct the pre-and post- elements (Vesala & Tuomivaara, 2018). These will be discussed in greater detail in the following sections.

Temporal liminality

A liminal period is a period of limbo, unique from the periods of time which surround it (Turner, 1982); an intense developmental time subjected to different rules and regulations which often acts as a doorway between the surrounding past and future where the individuals exposed occupy a position which is neither one state or the other (Borg & Soderlund, 2015). Liminality can be beneficial to those who live within it. The liminal period can be a time of creativity on an individual, organisational, or societal level (Soderlund & Borg, 2018). As a transitory period with different priorities, rules, and references, it represents an opportunity for growth and allows individuals a time to evaluate, explore themselves, and develop or trial new identities or behaviours or role models and can spark the development of new traditions or ways to work; liminal periods constitute an opportunity for a time of learning and development (Turner, 1969; Hawkins & Edwards, 2015; Soderlund & Borg, 2018). It is also suggested that it allows people to develop strategies for and be unintimidated by doubt in life (Hawkins & Edwards, 2015). Organisationally, liminality can be a beneficial situation as it has been suggested to have positive impact on creativity and the sharing and development of knowledge by allowing open, free conversation amongst colleagues which can move beyond the constraints of the more strictly-regulated office and allow ideas to develop (Shortt, 2015; Concannon & Nordberg, 2018; Vesala & Tuomivaara, 2018).

Physical liminality

For many, however, the pandemic is not only a temporal period of liminality. With large numbers of the population being asked to work from home, many established a physical liminal space in their house as they tried to work in conditions which had previously been assigned for other purposes, e.g working on the dining room table or in bedrooms. Spaces are constructed in two ways: physical structure but also how they are perceived and claimed by those who use them (Gieryn, 2000) and it is the users who impose use or transitory use upon those and can adjust the intended purposes themselves or manipulate it (Shortt, 2015). Physical properties of an environment can enhance the feeling of liminality but people define their own liminal spaces based on their reflections of the location and their position within it, and this may be different for different people (Shortt, 2015; Vesala & Tuomivaara, 2018). Liminal spaces, however, are typically undefined physical locations, typically a boundary or transition area such as doorway or stairwell, which have no functional role except to be the transition between other places of note (Shortt, 2015). In particular, it is often difficult to describe the liminal locations or define their role because it is unclear as to what it is except in relation to a separately defined location; it is a space where anything could happen (Turner; 1974). Yet liminal spaces can be more complicated than just being a transitionary location and can be essential to workers precisely for their lack of defined properties. Shortt (2015) discussed how liminal spaces offered a refuge from power dynamics in a hair dressing salon and how the people who worked there reclaimed the previously liminal areas as some of the only places that they could inhabit to escape from their presented working persona and relax.

Physical liminal spaces, however, are not always beneficial. Living and working without solid definition can cause anxiety and stress linked to not inhabiting space consistently or as expected (Beech, 2011). Organisationally, working liminally or within a liminal environment can potentially be an ostracising factor within the workforce leading to poor working relationships within departments (Tempest & Starkey, 2004) and organisations with liminal working as a common feature can also find that it damages the organisational learning process (Tempest and Starkey, 2004).

Impact of liminality on identity

Liminality, and the complexities that it establishes in living environments can have a significant impact on identity (Tempest & Starkey, 2004). Constantly changing environments and the period of transition, especially where external environments are subject to changes, can place identity in flux, encouraging individuals to regularly undergo identity work and reconstruction of the self. In social anthropology, liminality is commonly associated with rites of passage where individuals move from one social status to another. These transitions often invoke significant identity developments, but smaller scale identity changes can occur in less significant liminal periods. The alternative situation associated with liminal working can support individuals in rejecting social norms and encourages honest, free speech which can be useful for building relationships and opportunities (Sturdy et al., 2006). The liminal period acts as a catalyst for a series of identity transitions as individuals work to build a stable, coherent personal identity for the post liminal future which incorporates the lost past and lost future plans, and the changed present (Ibarra & Barbulescu, 2010).

Covid-19 represents a temporal period of liminality for everyone with many also experiencing physical liminality due to remote working, and this is likely to have a significant impact on people's lives. Not only will the pandemic have physical effects, the liminality of the situation and the uncertainty associated with both the liminality and the crisis is likely to impact people psychologically. This increases the likelihood of identity work and adaptation during this period which is likely to impact on individual and group behaviours, increasing the likelihood of disruption to the existing boundaries within the workplace.

7.4 Covid-19 and the NHS

As an unexpected problem which has threatened every person, organisation and country on every continent in the world, and prevented the continuation of a former way of life, Covid-19 represents a significant, global health-crisis (Kornberger, Leixnering & Meyer, 2019; Nembhard, et al., 2020) and one which looks to continue for many months to come as the world attempts to find a cure and vaccine.

The response to the Covid-19 crisis has varied from country to country, with governments and health organisations favouring different approaches. These ranged in agility and severity including lockdowns and mass testing to attempt to keep the infection rate low (Moon, 2020). Some countries' methods of handling the pandemic proved successful at impacting on the overall infection and death numbers, others less so. Uncertainties have dominated the scene, mostly about containing the disease and securing the best means to support the country and its people through the crisis, but also about the future and the secondary problems which have occurred as a result of the disease or the measures taken to combat it (Bailey and West, 2020). A significant aspect of these uncertainties surrounds the lack of knowledge about the full consequences of the actions taken; an inability to see the side effects and the impact on the individual of the actions made on a macroscale. In the UK, the pandemic has supplanted many of the former priorities of the country and has become the near sole focus of the government (Klasche, 2020). The infection rate of the disease has been the driving force for many of the changes implemented during the covid-19 period, many of which were based on those which were successfully used throughout previous SARS pandemics, however, although they did reduce the infection rate, Covid-19 proved more difficult to eradicate than earlier SARS cases because it is capable of transmission through asymptomatic carriers and has travelled the globe at a greater rate (Klasche, 2020). While they have reduced the infection and death rate, lockdown and the other measures that governments have taken to reduce the spread of the virus have also resulted in consequences beyond those which were intended, particularly in the UK. Additional problems of widespread unemployment, education problems, economic problems and secondary (non-Covid related) health problems, in the private and public sector, all of which look to continue to be problems in the future, perhaps even following the end of the Covid-19 crisis period, have arisen and this has shifted the Covid-19 crisis from not just being a health crisis, but a widespread socio-economic crisis (UNDP, 2020).

The current times can also be considered a period of liminality. Crises are already, by definition, unexpected, transitory events which divide history and create a before and after period (Kornberger, Leixnering, Meyer, 2019), very similar to liminal periods, which are transitory positions between two more strongly defined areas (Beech, 2011). The current Covid-19 crisis brought with it a liminal period: a temporary period of transition and flux from what used to be considered normal practice. The virus, and the measures which have been introduced to try and reduce the spread have changed the way of life for everyone and has resulted in the loss of a former way of life and a number of personal freedoms associated with it, for example being able to visit friends, or stand in close proximity with others.

The pandemic is also a good example of a wicked problem. With the number of significantly interacting factors, the high infection rate and transmission method, global transmission, no sign of a vaccine or cure, and healthcare problems with testing for the virus and insufficient PPE etc., it is not surprising that a number of researchers have described Covid-19 as a wicked problem (Klasche, 2020; Moon, 2020; Nembhard et al., 2020). However, as of July 2020, the Covid-19 crisis in the UK specifically is perhaps more appropriately described as a 'super wicked problem' as defined by Levin and colleagues (2012).

In additional to the defining features of a wicked problem laid out in the Rittel and Webber paper (1973), a super wicked problem must exhibit a time pressure, a weak level of government or authority trying to address the issues, a significant force discounting the seriousness of the threat, and a plea for a solution coming from people who are contributing to the problem (Levin et al, 2012). The Covid-19 situation in the UK, viewed on a national scale rather than as a series of local contexts, could be seen to meet these additional parameters. There is a strong time pressure to cure or significantly reduce the spread and impact of the disease notably for the sake of the population, but also for important factors like the economy, education, and the mental health of the population. During lockdown, the UK government implemented a number of lockdown policies, many of which caused controversy amongst the population, notably but not limited to the implementation of poorly defined mask wearing and social distancing policies in public places alongside a nationwide discount scheme for eating inside public eating establishments. These contradictions, the lack of a number of people abiding by the imposed regulations, and some of the publicly questioned actions taken by significant members of government could constitute a weak level of authority in trying to address the problem. The number of people disregarding the government guidelines, and those who spread personal or conspiracy theories represent a significant force who discount the seriousness of the threat; and finally there is a general plea from the public for the covid-19 pandemic to be dealt with efficiently by the government, despite a great number of the public continuing to disregard the protective measures. All of these points highlight how the Covid-19 crisis in the UK could be regarded as not just a wicked problem, but a super wicked problem.

The extent of the super wicked problem in the UK is significant. With no clear solution to the pandemic and associated time pressures, rapid decision making made to minimise the impact of the disease on the population as a whole did achieve a reduction in the infection and death rate of the disease but had wider consequences in a range of areas including: the economy, employment levels of the public, elective surgeries, mental health, education status of everyone in education. By acting on a wider scale in the interest of the public and focusing on the single crisis, it neglected to consider the effects on the individual level. Other wicked problems in the country like poverty and unemployment have been exacerbated by the presence of Covid-19 and risk significantly affecting even more lives.

One of the sectors in the UK most significantly affected by Covid-19 was the NHS, though the impact varied greatly across the country. Some hospitals were faced with overwhelming numbers of cases of Covid-19, while other hospitals or hospital services had low numbers of patients due to restricted services and patients avoiding exposure to the virus. To face the threat of high demand to Trusts across the country, guidelines were developed to support the distribution of patients and care (Savulescu, Persson & Wilkinson, 2020). Many Trusts had their services redistributed while other hospitals took on Covid-19 patients, to establish Covid-19 free care services, and many roles in the hospital were redirected to cope with the increasing number of patients. Crisis command structures, Gold, Silver and Bronze were used to manage how the system reacted to the demand, and policies and regulations were introduced and adjusted daily, sometimes more frequently, to try and ensure that the service continued to function and that staff remained safe. Resource sharing was increased between hospitals to try to ensure that every hospital was equipped with the supplies and PPE that it needed but despite this many hospitals also faced issues with insufficient PPE or virus testing capabilities for their staff and patients. In hospitals, many employees were required to change their work role, their job tasks, or their job location as they were shifted to different sites or were asked to work at home according to need or social distancing policy. Contrary to the usual methods of implementing organisational changes, many of these new policies were enforced rapidly and with little time to implement the changes.

Not only did the virus threaten the lives of those who were infected, it threatened every institution in the NHS and all of the employees within (Savulescu, Persson & Wilkingson, 2020) and brought about immense organisational change within the health sector. This is likely to have not only impacted on the organisations but the individuals who make up the workforce.

7.5 Organisational changes and their effect on identity

Organisations are social constructs made up of multiple units of people at different levels of authority working together, connected by social and relational bonds and identities which are developed within the working environment (Currie & Brown, 2003). Hospitals are particularly complicated organisations with interacting and sometimes competing departments that cover a wide area of knowledge and specialisms (Halford & Leonard, 2015). Organisational change describes changes which occur within an institution, whether changes to policies or procedures, or wider changes to a structure or culture, it occurs through management discussion and decisions which are then received and carried out by employees and the relationship and communication between these points is significant in how well the change occurs (Halford & Leonard, 2015). Whatever the scale, changes made at one level in an organisation affect others through the interactions and connections between departments and members of staff, and these changes, and the ambiguity which initially accompanies them will therefore not only impact the targeted department but also the organisation as a whole and the individuals who are employed by the organisation (Villiers, 2020).

When people start a role or a job, they undertake identity development to align with their new colleagues, environment, role they play, and the traditions of that place in order to reach an internal equilibrium (Giorgi & Palmisano, 2017). Their identity can then be further defined by their role, career, or the knowledge that they possess or contribute to (Brown, 2019); and people often integrate their career or professional knowledge with their identity more than they assimilate the institution itself (Anteby, Chan & DiBenigno, 2016). Affiliation with, and identity integration of careers or knowledge can be influenced by two key elements: callings, or specialisms.

Callings describe careers that people perceive to be their “purpose in life” (Hirschi, 2012). Individuals who feel attracted to these careers often experience their calling from a young age and are then driven to remain in that career for a significant proportion of their lives; common careers associated with callings include: actors, nurses, doctors, and pilots (Hayward & Tuckey, 2011; Fraher & Gabriel, 2014; Cinque, Nyberg, and Starkey, 2020). Literature exploring callings suggests that those who feel called to their career are likely to have an increased sense of dedication to their work and a high sense of meaningfulness, indeed callings are often associated with improved job satisfaction (Hirschi, 2012). Furthermore, those who experience callings are likely to have a strong sense of identity associated with the role, where the career is integrated into an individual’s personal identity rather than just their work identity. This can act as an identity anchor for the individual, protecting against identity crisis in cases of furlough or career uncertainty (Fraher & Gabriel, 2014), or supporting the individual and enabling them to work in potentially difficult conditions or face significant challenges without leaving their role (Cinque, Nyberg, and Starkey, 2020).

Specialist knowledge and membership of associated groups is often an important aspect of the identity of those who work in professional fields, e.g. doctors or engineers, (Alversson, 2001). Specialists develop these aspects of their identity early during the training process, and it often integrates with elements of their personal identity rather than just their social or working identity, influencing their personal behaviours, way of life and perceived future (Mallet & Wapshott, 2012). However this facet of identity is described as being intrinsically reliant on the continuation of the career and a number of papers have reported that people who integrate their work into their personal identity in this way can experience significant personal identity conflict if their work within the specialism is reduced or changed (Petriglieri, 2011; Conroy & O'Leary-Kelly, 2014). Small conflicts of identity can often be incorporated or adjusted to using narrative devices, but large discrepancies can lead the individual to move to reduce the conflict in some way, often resulting in the leaving of the conflicting workplace (Mallet & Wapshott, 2012).

Identity can be threatened by organisational or career changes (Petriglieri, 2011) but some careers are associated with greater identity flexibility than others. As discussed above, specialist careers are often heavily integrated into individuals' personal identities and so if significant changes occur to the work environment individuals can experience identity conflict (Croft, Currie, and Lockett, 2015). However, not all careers exhibit this trait. Careers which incorporate an element of identity flexibility into their job responsibilities are more likely to exhibit lower levels of identity conflict when new identity demands occur. Nurses, for example, incorporate identity changes and regulation of their emotions into their working life as they communicate with different social groups and under a wide range different circumstances (Hayward & Tuckey, 2011). In a crisis, these different levels of identity flexibility are likely to impact on an individual's ability to cope with the flexibility and identity stresses, with those who are accustomed to adjusting their identity as part of their role being more likely to be able to adjust to the changes imposed by authority with minimal identity crises or identity work.

Working arrangements, particularly location changes, can impact on personal identity. Translocality refers to situations where individuals spend time, in this case work, in a number of different places (Daskalaki, Butler, Petrovic, 2016). Translocality is inherently uncertain, the working environment is not defined and often occupies a location which has a different primary function, and these conditions create a liminal situation for people who work in this way. The liminal circumstances of translocal working can affect the identity of those who engage with it, particularly if it is an unfamiliar style of working or is combined with the employee carrying out different work to their standard job, because it can be hard to sustain a concrete present identity while navigating work and its associated roles without a fixed working environment (Daskalaki, Butler and Petrovic, 2016). Over time this can impact on personal identity, leading to identity work or internal strife in the employee (Conroy & O'Leary-Kelly, 2014) and high levels of stress, indeed people who live and work in liminal spaces long term have been found to focus on strong past and future identities as part of personal identity construction rather than focusing on the present as most non-translocal workers tend to (Ybema et al., 2011; Daskalaki, Butler, and Petrovic, 2016).

DiDomenico, Daniel & Nunan (2014) explored how working remotely, in particular through the use of virtual meetings and project management challenges traditional routines, working relationships, and rules of the workplace. This can lead to tension between employees as relationships between individuals with translocal workplaces have often been suggested to morph and distort with time, distance and the situation as contact and casual bonding opportunities are minimised (Swart & Kinnie, 2014; Lervik et al., 2010). Poor inter-organisational relationships pose additional problems for the institution as it reduces access to organisational knowledge, learning, and resources, which are often anecdotal, or increases the difficulty of accessing physical archives (Tempest & Starkey, 2004).

Individual's identities then, can be shaped and influenced by the way that an organisation communicates and enact changes and the way that they as an individual respond (compliantly or otherwise) to the events (Halford & Leonard, 2015) and this can then affect and cause problems to the working dynamics of the staff, affecting work rate and quality (Brown & O'Hara, 2003; Currie et al., 2010). It is important then, for organisational research and learning to consider not only the changes that they want to make to their institution, but also the impact that those changes will personally have on the workforce both short and long term (Brown, 2019; Hay, Parker, & Luksyte, 2020).

Given that organisational change can impact on individuals' identity construction (Hoyer & Steyaert, 2015), the identities of the workforce act as an indicator of the success or failure of organisational change and can be used as part of organisational research to explore the effects of the changes, successes and failures, and potential future implementations. By monitoring people's experiences and reactions to changes over a period of time, it is possible to examine the effects of decisions including both direct and indirect consequences, and that can be used to shape future decision making. It is essential, however, when carrying out organisational research, to not focus on the research subject in isolation, but to also consider the wider environments that the employees live within. Humans don't work in isolation, and they are not only affected by their workplace and colleagues, but also their home lives, non-work relationships, and past. Numerous factors will influence the way that they perceive a change, whether or not they consider the change to have succeeded or failed (Hay, Parker, & Luksyte, 2020), and the extent that they act compliantly to allow it to occur (Halford & Leonard, 2015). It is only by encouraging staff to discuss their lives in their entirety, covering all interacting elements, that the reasons for their thoughts and actions will become clear and can be used to better assess the impact of organisational changes.

7.6 Organisational changes and their effect on boundaries

Another area that can be impacted by organisational changes is the drawing and redrawing of boundaries within an organisation. Organisations are made up of employees who fall into interrelating units, held together by social and relational bonds (Currie & Brown, 2003). These units, or social groups, maintain their distinction through the development of boundaries, or social divides, between groups. There are two key forms of boundary within an organisation: social and symbolic boundaries. Social boundaries incorporate physical divides between groups of people, objectively exhibiting social differences through physical distance, or through the physical access to some type of resource, physical, social or emotional (Lamont & Molnár, 2002). Conversely, symbolic boundaries are conceptual divides between social groups, maintained through membership criteria determined by those within the social group (ingroup), and differentiation from non-members (outgroup) (Lamont & Molnár, 2002), following principles of the Social Identity Theory (Tajfel & Turner, 1986). The two types of boundary are not necessarily distinct and can interact with each other. Over time, symbolic boundaries can lead to the development of social boundaries between groups or be part of normalising or breaking down social boundaries. Social boundaries once developed can contribute towards the development of symbolic boundaries (Lamont & Molnár, 2002).

Boundaries between social groups can be affected by a range of factors. In particular, context and the cultural environment surrounding groups have been identified as significant drivers in the process of dissolving and developing boundaries (Lamont, 2000; Meier, 2015). Likewise, individuals who are not part of the social groups involved in the boundary have also been reported as being able to influence the formation of boundaries (Langley et al., 2019). While social, psychological, and cultural factors have been suggested to act as mechanisms driving the drawing of boundaries, there is currently little literature which describes the means by which they cause this to occur (Lamont & Molnár, 2002).

The boundaries between social groups can be supported discursively, with many papers noting individuals using language to position themselves and others as members (or not) of the ingroup (Barton, 2007; Heizmann, 2012; Copes, 2016). 'Othering' describes the use of language to reinforce symbolic boundaries between ingroups and outgroups, in particular by highlighting negative attributes of outgroup membership or associating their behaviours with stigma and shame, promoting marginalisation (Barton, 2007; Turner, 2007). Interestingly, this behaviour has been observed in both ingroup and outgroup members, and there have been a number of papers which look at how members of marginalised communities address the emotional impact of outgroup membership by positioning themselves away from the negative perceptions of that group (Barton, 2007; Copes, 2016).

Although boundaries are common within organisations and can be benign, they can also be damaging to individuals, and to an organisation. Aside from the marginalisation which can occur due to boundaries between social groups (Barton, 2007), discursive boundary establishment can lead to tensions within organisation. Remote working, with the associated physical boundaries between staff, has been observed to challenge and contribute towards distorted, or poor working relationships between employees (Tempest & Starkey, 2004; Lervik et al., 2010; DiDomenico, Daniel & Nunan, 2014; Swart & Kinnie, 2014). It is suspected that the Covid-19 pandemic, and the organisational changes implemented by the NHS which involved more staff working from home, are likely to contribute towards the development or redrawing of boundaries between the staff.

The treatment of staff in a healthcare organisation can have a lasting impact on the quality of care that they give to patients, staff absenteeism, and can improve the ability of the hospital to meet care targets (Dixon-Woods et al., 2014; Kline et al., 2019). Strong links have also been established between a supportive, positive working atmosphere and staff internal feelings of security (West et al., 2017), something that is essential to healthcare work. Covid-19 has been a significant exogenous event, and in addition to triggering significant organisational changes, contributed to increased levels of uncertainty which likely also impacted on people's identity and working practices. These changes are likely to have contributed towards the development or redrawing of boundaries between social groups.
A number of researchers have written about the importance of embracing the liminal period of Covid-19 and using this time to initiate positive, novel organisational change, working to both untangle the wicked problem of the pandemic and work into a better post-Covid era (Bogner et al., 2020; Cohen & Cromwell, 2020). By understanding what affected staff during the Covid-19 crisis, any social boundaries which emerged, and the mechanisms by which those boundaries emerged, organisations will be able to influence future changes to establish a positive working environment for their employees and a beneficial health service for the public.

Identity research is a useful tool to investigate organisations (Brown, 2019) and the development of boundaries between social groups. Collecting data from people who were affected by these changes offers an opportunity to understand the personal impact of the Covid-19 pandemic at work. The social behaviour in the workplace is one area which is likely to have changed during this period. Individual accounts and perspectives of their experiences provide rich information which can be used to not only monitor the shifting and development of boundaries within the workplace but also provide some insight into the factors which are responsible for the changes. Understanding the impact of the situation on the identities of the workforce and the way that they interact with their colleagues will allow the institution to determine the consequences of organisational changes on the workforce. This can be combined with the physical records and care statistics collected at the time for future reference to support healthcare workers and improve the quality of care that patients receive (Bailey & West, 2020).

The policies that the NHS implemented in response to the virus were widespread, sudden, and affected everyone who worked in a hospital to varying degrees, constituting a significant change for employees' lifestyles and their way of work. While the Covid-19 crisis has been difficult for everyone, as a period of liminality it can also act as a period of reflection and an opportunity for development to adjust the ways of working in the future both on an individual and organisational level. Taking the time to document these developments and the impact that they have on both the organisation and the individuals who work there will ensure that they are retained in the organisational memory for future benefit, and may, through listening to staff's experiences, also facilitating positive organisational-staff relationships which may support a better workplace environment.

7.7 Methodology: Exploring organisational changes and identity

Research which investigates a fluid, transitory situation such as the Covid-19 crisis needs to be equally flexible and creative in order to fully understand the lived experience of the healthcare workers who participate (Czarniawska & Mazza, 2003; Bailey & West, 2020). Narratives, as told by the individuals who live within a crisis, are a strong way to explore experiences and perceptions of the events and are already a commonly used method to explore people's experiences of liminality (Daskalaki, Butler, Petrovic, 2016). On a wider participatory scale, this allows an organisation to visualise the effects of organisational changes on the boundaries within a workforce and establish appropriate future measures.

Narrative memory and storytelling is already a foundation of organisational memory, with people passing down anecdotal information and support between employees, forming a support network to draw from and protect the institution from making reoccurring mistakes or support the organisation in times of worry or stress (Adorisio, 2014). Equally, creative discussion and storytelling are responsible for supporting institutional development and progression. Using similar narrative methods in a formal research process offers an accessible, familiar means for individuals to holistically investigate particular circumstances from a range of perspectives (Westwood & Linstead, 2001; Currie & Brown, 2003). Exploring the personal experiences of staff through the Covid-19 pandemic documents the consequences of the institutional changes which occurred during this period of time and stores them within the organisational memory ready for future events or proposed changes.

One of the most common methods for narrative methodologies is the use of personal diaries. Use of diary entries allows a participant to log their experiences over a prolonged period of time Diaries allow individuals to record their experiences and perceptions of events and introspect and consider their experiences in their own time and during, or shortly following, the event itself rather than allowing time and memory to elapse between the event and a subsequent interview (Bolger et al., 2003) which makes it perfect for monitoring the Covid-19 pandemic and organisational changes implemented during lockdown. Diary entries being filled out and controlled entirely by participants allows the reflections to be produced with relatively little external influence which will lead to rich data with naturally emerging emphasis according to the participant’s perceived significance, allowing themes to emerge and accurately represent the situation (Bolger et al., 2003). A collection of diaries from staff across a hospital produces a rich data corpus from which it is possible to observe the effects of organisational changes across the hospital and areas which are most significant to the workforce.

7.8 Project aims

The Covid-19 period has been a time of unprecedented change both for hospitals and trusts across the country, and their employees too. The transition and the changes implemented to minimise the risk of the virus may have resulted in a decrease in the infection rate and the death rate, but they could also have impacted significantly on the identities and boundaries within the workforce. It is essential that the changes are documented and evaluated to determine the extent of the consequences of the organisational changes, and to ensure that this knowledge is preserved to support staff during the following phases of the Covid-19 pandemic and in the future.

This project will investigate how the events of the Covid-19 pandemic and the changes implemented by the NHS have affected the boundaries between healthcare workers in one NHS trust. Specifically, it aims to determine the impact of context, and the social, psychological, and cultural mechanisms that lead to the formation and reconfiguration of boundaries (social and symbolic) within an organisation. By using diary entries to explore NHS staff’s thoughts and experiences of these events, and the impact that these had on their identities, it is hoped that it will be possible to assess some of the social impacts of the pandemic on healthcare staff.

Chapter Eight: Methodologies

8.1 Introduction

This study attempted to capture how the processes and changes which the hospital undertook during the Covid-19 crisis affected the staff members who worked there, with a view to incorporate it into the organisational memory for future benefit. To achieve this, the experiences and perceptions of staff members at the partner hospital were recorded over a three week period and interviews were carried out with two managers from the organisation. This chapter describes the protocols used within this study.

8.2 Ethical considerations

This project was initially part of a clinical audit project at the participating hospital, initial project proposal can be found at Appendix 12. A retrospective application was made through IRAS and granted (Application number: 286648) to allow the findings to be used for research purposes (Appendix 13).

Staff members' participation in this study was entirely voluntary. Potential participants were fully informed about the study and were given the opportunity to consider their participation and ask any questions prior to taking part.

All participants were given information sheets and consent forms before they took part which specified that they were happy for their data to be used for research purposes and published (see Appendix 14). All prospective participants were told that they were able to leave the study at any point that they wished without any repercussions and were assured that their data would be handled confidentially and anonymously at all points. Participants were reassured that they didn't have to take part in the study and could engage with it on their own terms to minimise the additional strain placed on them in an already stressful, busy period for the hospital. Participants were encouraged to produce their entries in any format or with any device they were comfortable with, and although asked to produce daily diaries were assured that they could answer less frequently if their current workload was too demanding.

Due to the personal content produced for the study and the proximity between the participants and the research team, a strict process was developed to protect the anonymity of the participants and ensure that no-one was able to trace their comments back to them. The point of contact with the participants was handled by one member of staff who stood on the research team, however, to maintain confidentiality they did not look at or listen to any of the transcripts. The point of contact passed the audio file directly to the transcription team, who were made up of existing administration staff from the hospital who were already familiar with handling patient data and working confidentially and securely. The transcribed files and any written diary entries were then passed on to the research team for analysis. The research team did not know any of the participants personally and did not have access to any of the names of the participants.

In recognition of the potential for some topics to be difficult or potentially disclose topics in which people were in dangerous or threatening situations, the information sheet did inform the participants that if anyone mentioned anything which suggested that they were in danger or risk of harm, that there may be reason to break confidentiality. Where concerning but not dangerous subjects were raised during the course of the project, participants were signposted to support networks.

8.3 Participants and hospital

<u>Participants</u>

All staff were informed about the project and invited to take part via a hospital-wide email. 28 people of varying roles and departments across the hospital volunteered to take part in the study; with the exception of having to be employed by the hospital, no inclusion or exclusion criteria were applied. Of the people who showed interest in the study, though many handed information sheets, a number of participants didn't submit any diary entries and so were discounted from the final figures. Overall, 13 participants (ten women, three men; age range: 24-61) submitted 97 diary entries over the course of the study, see table 2 for details of the participants and the number of diary entries submitted. Two additional participants were interviewed to gather contextual information and insight into the changes occurring in the hospital.

Table 2: Participant job title prior to the Covid-19 pandemic and during the crisis, and number of diary entries submitted during the course of the study.

Participant	Pre-Covid19 role	Role during Covid-19 crisis	Number of diary entries
002	Lab manager	Normal role	2
003	Team lead	Team lead (clinical)	5
004	Research nurse	Staff nurse	9
005	Ward Clerk – Ward A	Ward Clerk – Ward B	3

009	Director	Normal role	17
014	Physiotherapist	Normal role	10
015	Outpatient supervisor	Normal role and fracture clinic support	2
016	Department Manager (non-clinical)	Normal role	14
017	Business co-ordinator/admin team lead	Normal role with reduced hours	5
018	Appointments supervisor	Normal role with reduced hours	6
019	Manager (non-clinical)	Normal role	14
023	Doctor	Registrar medical cover	5
026	Consultant	Normal role	6
027	Clinical scientist/Manager	Normal role	Interview
028	Director	Normal role	Interview

Recruitment was open for a prolonged period to allow people to take part while managing their work, diary entries were accepted from 27th April to the 31st July. No participants submitted across the entirety of this period and many joined and dropped out according to their work pressures and demands. Participants who had dropped out continued to be sent email updates and were contacted twice to remind them about the project and encourage them to consider continuing to record more. If no further responses were received, these participants were not contacted again.

Hospital

The hospital which took part in this study is a small, highly specialised orthopaedic trust in England. In the months leading up to the Covid-19 lockdown (1st April) the Trust had undergone an organisational restructure where departments were regrouped into different units with new management structures and roles. This had not been long established when the measures to counter the pandemic were introduced.

During the Covid-19 pandemic, the Trust changed its standard operations significantly. A number of the specialist services offered by the hospital were closed, including the routine orthopaedic surgery elements which the Trust specialises in, and the chief executive of the Trust was called away to work in the newly established Nightingale hospitals in London. The site became a Covid-free hospital and took on some new services from nearby Trusts to enable them to better meet the demand for Covid positive patients and keep Covid-negative patients safe. While the hospital itself didn't take on significant numbers of Covid-19 positive patients, it did care for a small number of patients with the virus during the pandemic. A number of policies were implemented to protect staff from catching the virus, starting with a large proportion of the workforce working at home. Many of these policies were devised by the government or systems above the Trust itself rather than from management within the Trust and changed a number of times during the lockdown period.

8.4 Procedure and equipment

Diary entries

Staff were sent an email containing an information sheet, enrolment form and initial prompt sheet and given time to consider participating. Once they had completed their enrolment form, they were allocated a subject number to anonymise all submitted data. Participants were encouraged to produce daily entries for three weeks, but this was not enforced to minimise the cost to staff.

The initial prompt sheet, intended for their first week of participation, encouraged them to talk about their day and how Covid-19 had affected their way of work (see Appendix 15). Participants were instructed to spend approximately five minutes each day reflecting and commenting on the events of the day in an audio diary, although this was later amended to include written diary entries too to facilitate those who felt that they had an identifiable accent or were uncomfortable producing audio recordings. The prompt questions were deliberately open to encourage participants to talk freely about their experiences and the sheet encouraged participants to discuss anything else which they felt was of note, in order to broadly capture their experiences.

After approximately a week, the diary entries were analysed to identify any emerging themes. These were used to produce the prompts for the second week of diary entries. A second prompt sheet was produced and sent to participants who had completed approximately a week's worth of entries. Although the questions explored the emerging themes in more detail, participants were still encouraged to continue adding updates about their daily experiences and anything else which they thought was significant.

After a second week, the diary entries were analysed again to identify further emerging themes. These were used to produce the final set of prompts which were again sent to the participants accompanied with encouragement to also discuss daily experiences and anything else of note which might be relevant to the project.

Participants all started at different points in time according to when they signed up and not all participants worked full time. This meant that data from each set of questions was received over a wide range of time and there was no discrete time phase for responses. Furthermore, although each set of prompts were designed to be answered for five days, participants' workload and number of working days meant that this varied between individuals.

When all of the prompts had been produced, a final email was written and sent to all participants to encourage them to continue submitting diary entries with all of the prompts attached, Appendix 15. Although further recruitment occurred after this point, no further general reminders for participation were sent out.

Audio diaries were transcribed by a small team of audio typists who already worked in the Trust, and the transcripts were then sent to the researcher via the data manager who was the point of contact for all of the participants.

Interviews

Interviews were carried out with two of the clinical representatives on the research team, one of whom was the director of performance improvement and organizational development at the hospital, the other a manager and clinical scientist within one of the non-nursing hospital departments. The interview questions explored how the pandemic had affected their lives and working environment and how they perceived the changes which the hospital and higher bodies had implemented in response to the crisis, full interview schedules can be found at Appendix 16. Interviews were approximately an hour long and were conducted by the researcher using Microsoft Teams.

The recordings were transcribed using online AI transcription software (Trint) and were then analysed by the researcher.

8.5 Data analysis

Data were analysed by thematic analysis using the process described by Braun and Clarke (2006). Each diary entry was coded individually, and these were used to shape broad themes which were then used to identify themes across the whole data set. Theme shaping took place physically, each code was written onto an index card which were then laid out and physically manipulated to form groups, or themes. These themes were adjusted and refined gradually so as to represent the experiences of the participants accurately and were finally written up for the report.

In addition to this thesis, the findings were used to produce a management report, which was shared with the hospital director and executive team, and a display which was established in the hospital to share the findings with the hospital staff and public.

8.6 Researcher’s epistemology

To minimise the impact of personal preconceptions and thoughts, the researcher undertook an introspective diary before analysing the diary entries to allow her to identify any elements which might influence the analysis and perceived importance of some themes (Appendix 18).

Chapter Nine: Analysis

9.1 Introduction

A number of themes emerged across the diary entries but what was most apparent in the analysis was the incredible variety of experiences described by the participants. Each participant described a unique experience and perspective of the hospital: in terms of working location, department, and seniority within the organisation. Significantly, eight participants experienced some degree of change to their working roles, one of whom involved moving to working at home full time, and another five who moved to dividing their work between home and the hospital. Six participants had children at home that previously were in school most of the time, or who had lived away from the house, which changed their home dynamic and caring responsibilities, and impacted on their diary entries. This produced a wide range of perspectives and experiences which were explored in the data. Furthermore, the perspectives and experiences of the participants varied across the observational period. Participants produced diary entries at different points in time and were affected by different pressures and organisational changes which occurred in response to the pandemic. This variety impacted on the narrative of the data, as addressed by one of the participants:

> "*I think it's been the days have been so very, very different. It's quite hard to do one story for the whole thing*." (027, Mixed work locations (MWL))

Hence, although a number of themes were identified, relatively few were experienced equally significantly across the entire group of participants.

Across the diary entries, four key themes were identified which reflected the experiences and perceptions of the healthcare workers working through the Covid-19 pandemic. These were:

- Change
- Emotional impact of the pandemic
- Identity in relation to work role
- Boundaries between staff

9.2 Change

One of the most prevalent themes in the diary entries was that of change. All participants discussed the differences that they experienced throughout the pandemic, and there was an overwhelming recognition that life had "*definitely changed during Covid-19*":

> "*Because the change is huge. I mean, we're just we're just not the same department that we were, in terms of what we're doing*."(027, Manager, MWL)

> "*actually it's a different environment"* (028, Director, MWL)

The changes implemented as a result of the pandemic affected every element of individuals' lives and participants described the "*constant*" introduction of new changes throughout the observation period, and the "*relentless*" feeling of the pandemic and associated stresses. As one participant described relatively late into the observational period:

> "*The world and the new normal is basically you know you have to do things differently*" (009, Director, MWL)

These changes occurred in all aspects and environments of the participants' lives: at work, home and in the public domain, and not only affected the physical world, but also the way that people behaved within it.

The most apparent changes which affected the participants were:

- Organisational changes
- Individual changes.

And in many cases, these contributed to a sense of confusion and uncertainty within the participants. In addition to discussing the external changes, participants also discussed the work that they and their colleagues trialled and developed to allow them to work effectively in their new circumstances. Whether that be physical changes to processes, behavioural changes to support working at home, or plans for development for the future.

Organisational changes

Organisationally, the Covid-19 pandemic caused the hospital to undergo numerous significant changes to the building, organisation, and services. The greatest frequency of these occurred during the opening months of the observation period, though changes were still reported during the later entries. During the initial stages of the pandemic, a number of services were shut down and patients were encouraged to go to their homes where possible. These changes continued across the following months as services from local hospitals were taken on to enable the establishment of Covid-19 free zones in the region, and this prevented a return to normal services towards the end of the observation period.

For many staff, the biggest work change was location. Many employees across the hospital, including six participants, were told to work from home, either on a full time or part time basis, in order to reduce the number of people on site and minimise the spread of the virus. This was a very significant change in the hospital, not being something which the organisation had supported previously, and was regularly discussed by participants whether or not their working situation had been changed themselves; these reactions will be discussed in greater detail in a following theme.

With a great number of staff working off site and reduced services across the hospital, descriptions from members of staff who remained working on site focused on how quiet their working environments had become, both in terms of staff and number of patients. Reduced services meant that the wards themselves had few patients on them, while some services saw no patients at all, and many participants discussed the impact of this on their working habits and the way that their departments saw patients. The introduction of social distancing measures, and the increase in numbers working from home also meant that the wider hospital environment was quieter, particularly the main corridor which was reported as being a common point of verbal communication prior to Covid.

Many diary entries also featured references to a recent organisational restructuring which had occurred just a couple of months prior to the onset of the pandemic and the introduction of lockdown policies. The restructuring involved a number of great organisational changes, many of which had not fully settled before the pandemic occurred, and it was suggested that this had added further challenges to coping with the pandemic, as one participant described:

> "[because of the restructuring,] *lots of people are managing different areas than they were so they're getting to know new teams as well. So it's been trickier for them, I think*." (027, Manager, MWL)

One of the most mentioned organisational changes, associated with large numbers of staff working off site, was the move to online working. Shifting meetings to online means of communication such as Microsoft Teams was a significant change which many of the admin and managerial participants discussed, though some described finding it a more stressful means of communication than being able to conduct meetings or communicate physically.

Virtual means of communication were not only present for work. WhatsApp was commonly mentioned by the participants, both front line staff and home-workers, as a positive means of communication between employees both for work and non-work functions. Many participants mentioned the additional emotional support that the chat group offered and the means by which it supported stronger group cohesion and bonding.

Smaller changes also occurred on a departmental level. Following a series of complaints about email etiquette, for example, one participant discussed the measures that their department had introduced to ensure that work continued to progress efficiently and that stress due to the work was minimised:

> "*Within our small team we have a "rule" that emails should be acknowledged within 48 hours. Doesn't necessarily mean you have to answer, but just get back to say, "I've seen this and will get back to you by such and such a date etc". We're not perfect with this, but we're making inroads to keep on track of things*" (016, Manager, WFH).

The logistics department too reported increasing the amount of time that they had PPE and associated stock prepared for, and described working towards being fully equipped and "in a state of readiness for every eventuality", even those which had not been announced.

Perception of organisational changes

The organisational changes triggered by Covid-19 had a big effect on the workforce of the hospital, and many of the diary entries addressed this. Participants regularly discussed their experiences and understandings of the changes that affected the hospital and the means by which they were implemented, though the reception of the changes varied across the participants and the period of time that the diary entries were produced.

Speed of organisational change

Changes to the organizational policies, and the introduction of new procedures passed out to the were regularly discussed. Initial discussion about the changes imposed around the hospital focused on the variety of changes which were made to the processes, and the speed at which they occurred. Many participants noted that decisions and changes were being made at speeds much faster than they previously had before, and this provoked a number of responses. Responses to this speed fell into two camps: those who felt that the speed was too much, and those who felt that the speed was beneficial for the hospital.

Rules and procedures devised for the Covid-19 period were described as different rules, having no similarity with earlier work:

> “*There is no parity, there is different sets of rules. You have no idea what’s going on in the place at all from one minute to the next. The left hand doesn’t know what the right hand is doing*.” (003, Team Lead, WOS)

One participant described the rate at which decisions were being made, describing a single NHS England poster as being changed three times in one hour. The early diary entries which were recorded during the period of most change within the hospital described a chaotic scene, and one participant discussed in length how in the opening of the transition to lockdown they had found it difficult to determine where they were supposed to be working because of significant disparity and confusion across members of staff regarding knowledge of the new systems.

However, many of the managers and senior figures of the hospital who participated in the study described the benefits of the initial freedom to make decisions:

> “*We had to make decisions initially. There was this heady rush of we can do what we like now. This is great. And we were just making decision, decision, decision and a little bit of referring up. But generally, nobody knew what was going on and they were happy that we just made them. And it felt quite liberating*.” (027, Manager, MWL)

Indeed, the contrast between the speed at which the Trust, and departments within the Trust, were able to make situationally specific changes was described as a benefit in contrast to the previously much slower system of developing change. Most of the managers who participated were quick to support the opportunity to tailor changes specific to the people those changes would affect and the chance to move quickly, rather than being restricted by standardised systems and legislation.

> “*But generally, the more the hospital can free up individual areas to do their own thing, I think the better it has gone*.” (027, Manager, MWL)

> “*And I saw the NHS move a pace I’ve never, ever seen. And it was so excited. I came from private sector before, you reckon logistics. So it was really quite fast moving. And it’s always been something I’ve struggled with is the pace. And it’s been amazing. Bureaucracy went out the window. Decisions will get made really quickly.*” (028, Director, MWL)

This speed, however, did not remain throughout the entire observational period, and noticeably reduced across the observational period as bureaucratic processes were reintroduced and changes were slowed:

> "*So if you look at trauma, trauma moved to us in two weeks, I've been battling for two months now to get an agreement of when it's going to go back. So we're almost getting back into the time scales. I've got a day in September. I don't believe it. It'll be November or likely longer. Even that's fairly quick for the NHS. But that gives you an idea of the timescales. I am seeing bureaucracy creeping back in. […] and it's slowing us down*." (028, Director, MWL)

Reception of the new way of working

Staff redistribution and role changes were some of the most common discussion points surrounding the change. Most of the participants experienced a change to their role and the location in which they worked, either on a full time or part time basis, whether that was a change to the work that they were doing, or the location that they worked from. Several participants taking on additional work or shifting the weighting of the roles which they already held.

> "*It is just quite funny really that getting involved in things that we never really would have imagined and is certainly not in my normal skill set*." (009, Director, MWL)

Staff reacted very differently to their new roles and the changes which occurred as part of it: some described little personal impact, while others experienced large amounts of stress due to the changes which occurred around them, explored in greater detail in following themes. The variety in reception to changes across the hospital and the demands of the pandemic was best summarised by the following:

> "*People have ended up playing to their strengths and playing a role, which may not be their title or the employed role, for what's needed in this current situation. Some people have adapted really well. Some people haven't*." (028, Director, MWL)

Participants' perceptions of the changes and the way that it affected their working were regularly mentioned in their entries.

Many of the people who were told to work from home, in this data set: admin, management or directors, appreciated the benefits which remote working allowed them, describing it as "great", or something that they were enjoying. And while many acknowledged difficulties associated with working from home, there were many reports of participants working better from home, notably describing improved concentration and work quality due to fewer distractions while working at home, or fewer people being in offices:

> "*My concentration, focus and turnaround time for complex work areas has benefited immensely from not having the office noises*." (016, Manager, WFH)

The ability to use their former travel time for other activities was also appreciated.

Of those who remained on site, a number still described the new practices as having elements which functioned better than the old style of working. Although the differences between the two styles were acknowledged, several participants said that they enjoyed the new way of working and found it exciting.

> "*I quite like the way that we are working now. I think it's more flexible and actually patients don't lose out*" (014, Physiotherapist, WOS)

> "*it enabled me to revisit some skills which I quite enjoyed actually and I quite enjoyed the new challenge that this is providing*." (004, Nurse, WOS)

Perceived benefits to the new way of working included: working better for patients, giving them the time that they need to have the best therapy possible; allowing staff to have a better appreciation of the other departments in the hospitals and how they work/interact; and not feeling rushed when carrying out medical rounds; and having the extra time needed for patients and their other colleagues.

Adapting to a new working environment

Many of the responses to organisational change involved adaptations by employees to work within the new rules and systems. A number of these were small changes, personal actions implemented by the individuals to support themselves during the changed way of working: one participant described moving working location within their house so that they were not in close proximity to family in order to reduce stress and conflict about spending time with their children while working, another participant described choosing to stop wearing a watch due to changes in the lockdown, and an individual who struggled with the demands of Teams meetings made an effort to carry out some meetings through phone calls to reduce their stress levels.

Some of the changes were more widespread. These changes were typically responses to the threat of Covid-19, like reports of staff minimising contact in the hospital:

> "*It is strange when you walk past someone, we all kind of step back and shy away, I find this more noticeable at work when walking on the corridor*."(003, Team Lead, WOS)

A number of participants commented on the ending of physical contact between staff which arose in response to the pandemic. With two participants finding the lack of touch difficult because they felt that it reduced staff relationships and their ability to pass on reassurance, something which was deemed particularly important during the stressful period.

But there was also a report of a change in the way that clinical staff behave regarding handwashing and their uniform:

> "*But, really I suppose it's made me really focus on the hygiene, the infection prevention control and what measures I can take to limit cross contamination and to limit kinda taking the virus anywhere, […] I think a lot of people would wear their uniform to and from work, whereas people are very much not doing that now, you don't see people wandering in in their uniform and going home in it. That's a massive change that I've seen and a culture change*," (014, Physiotherapist, WOS)

Individual changes

Change was not only seen in the physical alterations of work life, most participants also discussed how they had noticed that they and others had experienced changes at home and in their behaviour as a direct response to the events of the pandemic.

Domestic changes

Home life experienced significant changes during the pandemic. Many participants described spending more time at home whether because they were working at home or because of the implemented lockdown, and a number discussed changed family situations as schools were shut, or as grown up children moved back home. For some these changes were considered minor, or even positive, and required relatively little change from the norm, while for others, having more family members in the house caused increased stress levels. The inability to visit family members, whether due to lockdown or the inability to use public transport safely, was also a regularly mentioned change to home-life and one which caused a significant amount of stress and upset to participants, particularly when family members were sick or disabled and struggled to communicate through virtual means.

Activities outside of work also changed and participants regularly described the contrast between their non-work life activities which they had engaged with pre-Covid-19, and those which they had been able to continue or adapt to the new circumstances. A number discussed not being able to engage in their desired activities due to Covid-19 limitations. Participants described being cut off from their usual activities like the gym and massages, and how this and not only affected their activity levels, but the social support network that those locations represented. Physical activities were limited to those which could be facilitated online, or which could be carried out around the house and garden.

Domestic behaviour changes

Lifestyle changes and associated behavioural changes were common across the diary entries. Participants discussed the things that they had noticed changing or had actively set out to change during the Covid-19 period. Many of these changes responded to the changes of circumstances, for example those whose families found themselves all living in the same house again or limited in their activities with young children. Though all were affected by the increased amount of time at home which arose from the nation-wide lockdown. For many, these behavioural changes were positive:

> "*So I've been doing cooked breakfasts, I've been doing Sunday roast dinners, all sorts of things just for the fun of it*." (027, Clinical scientist, MWL).

Some, however, were more difficult for the participants. One participant wrote about how they noticed a change in their decision making, and how they found that it had become more difficult for them to make decisions about their home life "*because every choice seems more important*", although they noted that their work and shopping decision making was unaffected.

Outside of work some participants described changing their behaviour to take advantage of the lockdown, prioritising using the time for other means. One participant described people responding to the pandemic on a spectrum between two camps: those who see it as something to endure and live through until normal resumes, and those who see it as "*the opportunity to change everything*": an opportunity to try new things or provoke some element of change. New priorities were developed for the circumstances, with some taking the time to do more things that they enjoy, and others aiming to use the time constructively, as a period for enjoyment and learning. Across the data set, participants described developing new skills e.g. instrument playing or crafts, seizing the opportunity to spend more time with family, developing fitness and healthy lifestyle, DIY projects, and fun activities like watching the full Marvel universe films. A number described spending more time talking to family or friends (using virtual or socially distanced means) than they did prior to the pandemic.

Shopping was a common situation for behaviour changes. A number of participants described changing their shopping habits, whether due to being nervous or for lockdown purposes, and their choice to avoid physical shopping, favouring online ordering or click-and-collect services. One participant in particular described particular changes to their shopping behaviour to only shopping during hours where the supermarket was relatively empty, saying that they would turn around and go home if they saw a queue of people outside the shop.

Coping strategies

Common behavioural changes involved personal coping strategies that participants found themselves engaging with as they worked to process the changes happening around them. Many described being cut off from their usual de-stress mechanisms or activities because of the lockdown which had been enforced across the country:

> "*I used to go to yoga three times a week. […] So, yeah, definitely I think impacted on, on that side of things 'cause that definitely was something the yoga side of things definitely that I used a lot to de-stress*."(003, Team Lead, WOS)

The combined impact of the pandemic, loss of physical support from family or friends, and loss of access to a number of these de-stress activities affected a lot of participants. Many described developing strategies and undertaking enjoyable activities to help them "*recover*" or "*keep sane"* through the difficult period, contrasting with the descriptions of stress and relentlessness which were often used to describe the changing working situation. These activities had a big impact on the mental wellbeing of the staff involved and supported them in improving their work life balance and stress levels.

Nearly all participants also discussed changes in their behaviour which occurred as a result of the effect of the Covid-19 changes on their lives, and the way that they engaged with different activities to take a break from the pandemic or reduce stress:

> “*I have never, I mean I’ve always enjoyed my garden, but never to the extent that I have in the last few weeks. It has been a real place where I have been able to actually focus on something different from COVID*” (009, Director, MWL).

For many, these coping strategies took the form of positive activities: increasing levels of activity or exercise throughout the day or engaging with hobbies. Though others described disengaging with social media or the news to cope with the stress of the pandemic.

Many participants described increasing the level of contact that they have with family or friends, whether socially distanced or virtual, as a response to the pandemic or the stresses brought about by the changes. Many mentioned talking to family over the phone every day, while one commented that they spent more time in e-meetings with friends than they used to spend physical time prior to Covid-19. Talking to other people also provided support – whether that was line managers or colleagues as some described, or a group of people in other meetings, e.g. weight watchers. Discussing the problems was mentioned a couple of times, allowing participants to focus on their wellbeing and talk through their challenges constructively.

Building in breaks and time not working was a behaviour which people described using to cope with the stresses of the period. Both additional sleep –as adjusted sleeping patterns, lying in, or napping- and breaks or holidays were commonly mentioned by participants as a significant area of support against the busy lifestyle which many were facing. One participant in particular mentioned that a good day was “*helped by going to bed earlier*” and regularly discussed the impact that sleep had on their wellbeing. Others mentioned falling asleep on the sofa or sleeping in because they were exhausted. Some participants described actively introducing periods of rest into their routine, either by building small breaks into the day or taking a holiday, to ensure that were able to cope with the increased demands of work and stress and burnout:

> “*As far as my actual practical day was concerned, it certainly felt a bit better because I had a few breaks in the day, and wandered around the garden, even if it was just for 5 minutes, which was really good. I still managed to clock up 8 hours of Teams meetings over a 10 hour period but at least I had a couple of hours dotted through the day that made it actually feel a lot better*.” (009, Director, MWL)

> “*I still took the week off because I recognized that I’d been working full out, and this was going to be a marathon. And I felt real guilt around taking a week off*

> *from work when this was all happening. But I also recognized if I didn't, I'd burn out*."(028, Director, MWL)

Not all of the coping strategies engaged with by participants were constructive, however, and a couple of participants discussed the negative coping strategies that they had found themselves engaging with during the period. Two participants wrote that they had noticed that they had fallen into comfort eating cycles as a result of lockdown

> *"[I] needed some food when I really wasn't hungry and I ended up picking at all sorts of things in the house and I think that also made me feel rubbish because I know I've put on a few pounds and was just generally feeling a bit low and yeah it's a cycle that I think we probably all recognise: that you feel rubbish, you eat something, you feel even more rubbish, you eat something else*." (009, Director, MWL)

One participant also recorded that they were "*definitely drinking more*" as a response to the stresses of the pandemic. These, combined with a lack of exercise, also contributed to weight gain which both participants described as having a negative impact on their health and wellbeing. Both participants discussed a need to control these coping strategies in their entries.

9.3 Emotional impact of the pandemic

The mental and emotional impact of Covid-19, and the thoughts and feelings of the participants were encouraged and regularly mentioned in the diary entries. The following emotional subthemes were identified across the entries:

- Confusion and uncertainty
- Stress and burnout
- Guilt
- Work-life balance

Confusion and uncertainty

Confusion which occurred as a result of the pandemic and the ensuing organisational changes was also regularly mentioned in the diary entries and lots of people discussed high levels of confusion across the workforce in the initial onset of the pandemic. The early stages of the pandemic incorporated lots of changes to the organisation, and many participants mentioned experiencing general and personal difficulties adapting to the new situation. Others described the situation as "*chaotic*" or "*dysfunctional*", or found the whole situation confusing, a feeling that was enhanced by not knowing where to find support and the perception that staff did not have "*clear, definitive answers, about what they need to do*". Much of the confusion occurred in relation to the policies and processes implemented both by the government and the hospital to mitigate the impact of the pandemic. The earliest diary entries described significant levels of confusion during the onset of the transition to lockdown, particularly in the initial period of job relocation and change. Wider confusion about the virus and effects on the country were also present.

Tied into the changes which were occurring was uncertainty, which was mentioned throughout the observational period. Participants regularly discussed personal situations at work where the changes had left questions or gaps in their circumstances. Most were linked to a lack of communication about the changes or were localised to particular roles, for example, about whether medical exams were happening or when the gym would be ready for use and how it could be used with social distancing policies. This uncertainty had a tangible impact on one participant who explained how feeling unsettled by the virus and the hospital affected their worries at work:

> *"I think I am worried about [whether I can get my uniform out of the closed ward] but I think, I think it's more a symptom of generally being a bit unsettled and then you just focus on the little things that, that really I know are completely solvable*." (004, Nurse, WOS)

Stress and burnout

The most common emotional response to the pandemic and associated organisational change was a prevalence of stress and burnout symptoms. Reports of higher stress levels, and associated signs of burnout and exhaustion were common in descriptions of the early phases of the pandemic, though the degree that individuals were impacted by the situation varied significantly from:

> "[*It was] certainly very tiring early on*" (027, Manager, MWL)

To:

> "*Two weeks in I had a "moment" […] I misread the email and was convinced I was going to have my laptop taken away. This had me in tears and ready to chew somebody's ear…*" (003, Manager, WOS)

Further examples of stress and burnout were exhibited in individuals who perceived that their jobs had changed significantly or who felt that they were doing more work or working longer hours than normally expected of them. A number of people used words like "*tense*", "*draining*", "*relentless*", and "*total exhaustion*" to describe their working lives during the pandemic, while others described working through the early stages of the pandemic as "*chaotic*" and like "*firefighting on a daily basis*". These negative emotions were also attributed to impacting on energy levels and mood, compounding on the demands of the pandemic and the organisational changes across the hospital.

Many triggers to the stress and emotional toll arose because of significant changes to work responsibilities and associated tasks, where participants were required to carry out jobs which were "*not in my normal skill set*". A nurse describing their transition from their pre-covid role to the position that they filled during the crisis, described how the staff around the hospital were "*overwhelmed*" by the sudden adaptations which were occurring and the changes they had to adapt to. While a consultant discussed the "*stress, anxiety and discontent*" that they and staff that they worked with experienced, linked with the additional work pressures and responsibilities.

These negative emotions were extended beyond the participants themselves. Participants who were responsible for offices or departments described the ways that they perceived that the pandemic was affecting their colleagues. These descriptions were similar to the personal experiences with other staff being perceived to be very tired and struggling with the relentlessness of the situation, and "*all ready for time off even to sit at home*".

Some of the low emotions were directly associated with sleep or lack of sleep. References to being shattered or mentally exhausted were common, and a number commented changing sleep pattern or reported poor sleep quality over the course of the diary entries which often correlated with intense descriptions of stress and burnout linked to their job. One participant who decided to cycle to work discussed how the activity increased their tiredness levels, and impacted on their home life and sleep habits, making them more tired around the home and unable to give their full attention to their family.

Some participants described struggling to leave the stress of work at work: one described being unable to relax, while another described thinking about work and stresses of work even while they tried to carry out activities to reduce their stress.

> "*But even in the garden I'm thinking about work. I'm thinking about the service that we're providing. I'm thinking about the number of staff that can't do, or can't be on the weekend rota because they're at risk from a respiratory*

> *perspective or they haven't had the fit mask testing to be able to join in with the weekend service.*" (014, Physiotherapist, WOS)

One participant described very high levels of stress associated with working and described struggling to stop working, increasing the amount of time at the desk in a day, and patterns of working sporadically even on their day off.

Comments referencing stress and burnout generally decreased after bank holidays and or holiday periods, while one participant who had to work through a bank holiday continued to make comments in line with stress and burnout in their entries. There weren't enough participants who submitted entries over a long enough period to assess whether this was a consistent pattern across all participants.

Stress and worry were not only experienced in the workplace and many participants described concerns or problems which had arisen in personal lives. This commonly manifested as stress or exhaustion associated with worry for vulnerable or sick relatives but was often associated with not being able to access the traditional means of support that they had prior to the pandemic. The inclusion of problems and strain outside of work led to participants with severe home-life or family problems describing persistent worry or feelings of unsettlement, and high levels of stress, anxiety and exhaustion. One participant in particular described being so affected by stress outside of work that they struggled to look after themselves, while another participant described trying to contain home and work worry to their respective locations to mitigate the additional strain.

Guilt

A number of participants included feelings of guilt in their diary entries. This guilt fell into two categories: with those who worked from home and who had family living with them tending to exhibit guilt about their time distribution, and those who experienced changes to their working patterns describing guilt about their working levels.

Guilt surrounding family

Of the six staff who reported having young family members living at home, four explicitly discussed feeling guilt and conflict about the amount of time that they were able to interact with their children.

> "*One thing I had never expected to feel I think is guilty, but I think you know it is like the kids are at home, you know they don't, they're not going to school at the*

> *moment and you know I thought it would be, oh it's going to be you know, it will be lovely and but I think I feel like I'm seeing less of them now than I did before […] and I just feel like I'm, it feels like more work than mum*." (003, Team lead, WOS)

Some of this pressure came from the self-perception that they were not spending enough time with their children, or not supporting them with their home schooling (all children were prevented from going to school during the lockdown period and had to learn semi-independently at home). One participant also discussed how tensions had arisen within the family as "the *rest of the family find it difficult with me being literally on meeting after meeting after meeting and not having time to even come out and speak to them*.", and how this pressure contributed to their feeling of guilt.

Guilt surrounding work

Those with changed working patterns were also very likely to experience feelings of guilt (five out of eight), and these were generally related to feeling guilty for working reduced hours when colleagues were continuing to work as normal or were facing increased pressure or responsibilities at work. Although the reason for not working was rarely due to the individual's personal choices but was a result of a choice made higher up within the hospital to try and minimise the risk of spreading the disease across the workforce. The impact on the individual, however, is was best summed up in the following comment:

> "*To maintain social distancing in our usually rather compact and bijou office we have had our days reduced and are currently working on a rota. It has worked out that I am doing two days a week. There are some feelings of guilt that I am not doing enough*." (018, Appointments supervisor, WOS RH)

> "*Another member of staff is at home because her partner is shielding. And we've decided that it's safer for her to be away. And she's found it hard in terms of guilt, really, about what she's not able to do*." (027, Manager, MWL)

The guilt was also discussed as a factor which increased stress levels. In particular one participant described how their department remained stressed even when work was reduced due to feeling guilty about not contributing equally during a stressful time:

> "*As a team we discussed that although it's stressful to be busy it's also stressful being quiet and we could all imagine everywhere else being busy and discussed that that made us feel quite guilty.*" (004, Nurse, WOS)

This participant and others described actions that they took to attempt to minimise their feelings of guilt or absolve themselves of the actions which incited the guilt. For most this took the form of statements of absolution which followed the initial declaration of guilt, where the individual justified why their actions were necessary and shouldn't be linked to feelings of guilt. For example, a director justified taking a holiday during the initial stages of the pandemic by emphasising the need for the hospital to have a director with high energy and attention who could prioritise dealing with the problems within the hospital without also battling burnout:

> "*And I felt real guilt around taking a week off from work when this was all happening. But I also recognized if I didn't, I'd burn out. And actually, they needed me for the long term.*" (028, Director, MWL)

Work life balance

Work-life balance was a significant factor in the emotional impact that participants faced as a result of the pandemic. Eleven of the participants actively described increases to their working level as a result of the organisational changes and the pandemic, and some of these described ways that the increase in work affected their home life or work life balance.

The level of work that people were undertaking was sometimes described as problematic. A manager described the people they worked with, saying that many employees were "*drowning in work*", and suggested that the inability to pick up additional work was causing problems and frustration within the department. Working a full day with no breaks was common in the diary entries of some of the participants who were working from home who also described starting work early and finishing late on a regular basis. In a later entry, one summarised this level of work in the following statement:

> "*I joined the NHS 30 years' ago and I can honestly say that I've never worked for this length of time at this intensity and it's sometimes a bit difficult to make sense of that*" (009, Director, MWL)

One consultant described finishing late and arriving at home at two in the morning, and then returning to work the next morning to present a webinar, while another was so busy that they took a break from participating in the study so that they didn't fall behind with work.

Supporting others was a common element which contributed to increased demands at work, one participant described feeling pressure to help other people during the difficult period and this contributed to an increased workload and reduced work-life balance. Managerial participants often mentioned increased levels of staff support and talked about how the pastoral elements of their roles were taking up more time than they had previously:

> "*I've spent a huge amount of time talking. I was reading back through my diary reading: "I've got nothing done today, I've just been talking all day." So a lot of work, you know, was just walking around and talking to people, and I'm sort of trying to come to an understanding that that might actually be work*." (027, Manager, MWL)

Beyond working additional hours in the working day, others described how work had begun to be present in their home lives. One described "*I'm literally dipping in and dipping out of my emails to make sure they are all okay*" while at home; one participant described struggling with not working on days off; while another expressed frustration at having to solve a work problem via text on their day off.

One participant described their work-life balance as "*non-existent*" and "*atrocious*", while two others discussed the need to regain a suitable work-life balance in the near future, emphasising a need to consider reprioritising down time and restoring balance between work and life.

Good work-life balance

Three participants described a good work-life balance. These participants were generally staff who had continued to work on site in the same role that they had prior to the onset of the pandemic and who worked in generally well-staffed departments. The closing of the hospital services contributed to reduced workload with less urgency compared to normal. One described their work-life balancing shifting positively to mean that after-hours working was no longer necessary, while another discussed how their department had become more aware of trying to maintain a good work-life balance for their staff. The third participant discussed taking on a more flexible approach to work-life balance, preferring to integrate some personal work into their scheduled working hours, and some paperwork and emails into their home life. They suggested that working in this manner allowed them to develop a "*great*" work-life balance for them.

Changed over time

Work-life balance was not always fixed across the observational period. Two participants mentioned how their work-life balance had changed over time, both describing initial onset of additional work which was “*overwhelm[ing]*” and contributed to a poor work-life balance. They both then discussed how they had developed a better work life balance equilibrium for themselves.

9.4 Boundaries between staff

While good working relationships and camaraderie were developed between staff who continued to work on site through the pandemic, physical distance between staff was a very common point of discussion across the participants and was often at the heart of points of conflict within the diary entries. There were two significant areas which catalysed disconnection between staff:

- Disconnection due to the introduction of remote working
- Disconnection due to location in the hospital

Disconnection due to remote working

The implementation of remote working to a large proportion of the staff was a regular topic of discussion in the diary entries, both from those who were working at home and those who were working on site, with very mixed responses. Some discussion about the conflict and tension between staff members was blatant, with participants bluntly discussing the tension between home and site staff, (or clinical and non-clinical staff, where non-clinical staff were more likely to have been given the opportunity, or direction to have worked from home), while others prioritised other subjects.

This disconnection occurred over a number of topics:

- Perception that home workers were not working, or not working as hard as site-based workers
- Perception of inequality based on who was able to work from home
- Communication difficulties and team interactions
- Absence of understanding why working from home was important (Covid)

Perception that home workers were not working, or not working as hard as site-based workers

One of the most common perceptions underlying the tension between home and site-based workers was that some people who were working from home were not working as hard as they were expected to on site, or that they were not working at all. Some individuals described concerns about people working at home taking advantage of the opportunity to do little work:

> “*Some people are working from home but there are some who don’t seem to be doing an awful lot and this has been picked up by their colleagues*.” (018, Appointments supervisor, WOS, RH)
>
> “*other people are getting away with not actually working, not working at all [...] It’s wrong*” (005, Clerk, WOS)

This understanding that there were some staff who were at home not working was perpetuated by staff in conversation, even where there was no objection or criticism of the behaviour:

> *“So how much do you ask people what they’re doing at home? So we’ve fallen into the ‘Not at all’ camp because we don’t want to know, because some staff aren’t able to do stuff at home. What does a medical secretary do at home when they haven’t got access to medical records? And the answer is, I have no idea. And please don’t tell me*.” (027, Manager, MWL)

However, these perceptions were contested by some of the participants who were working from home. Many of the participants who worked from home described working longer hours than when they had worked on site, and some had described having to undertake additional work to overcome challenges which had arisen due to working from home. One participant working from home described facing accusations that they were not doing any work despite feeling that they were working hard:

> “*There’s a nasty undercurrent at the minute that I feel that is targeted towards those of us who are home working. We were told to go and work from home to reduce the number on site but some are suggesting that we’re sitting at home. I’ll give today as an example, I’ve been logged on since 7:30 and I’m still working at 6 and haven’t finished yet*.” (016, Manager, WFH)

Perception of inequality based on who was able to work from home

The inequality of the distribution of the opportunity to engage in home or flexible working was a notable point of discussion by participants who were unable to work from home. One participant who had not been offered any home working explained how the opportunity had not been equally offered across the hospital and was a “*bone of contention*” within the department in which they were based. This was similarly expressed by another participant in the early stages who described increasing feeling of resentment across the workforce who had worked on site through the pandemic due to inequality surrounding remote working:

> "*It became very apparent to me over the last few weeks just how very dissatisfied a lot of people in the Trust are, and this mainly due to them feeling that they are being unfairly treated compared to their colleagues. […] Now this isn't just me, this is across the board: this is nurses, this is HCAs, Ward Clerks um ad admin, this is constant, this is what you are hearing all the time from the people who are turning into work and working their normal hours every week.*" (005)

Communication difficulties and team interactions

Miscommunication and rumours taking place amongst the staff were suggested to enhance the tension about remote workers, particularly regarding the necessity for staff members to be working away from the site. One manager described how gossip and miscommunication from people working on site contributed to and enhanced feelings of isolation and upset surrounding staff members being asked to work at home for their own safety:

> "*What I do not appreciate is hearing comments attributed to him third or fourth hand that I won't let him back to work and being asked if there is an agenda. The risk assessment holds regardless of if boredom is an issue or not. I have had several conversations with the staff member and find it increasingly frustrating*." (002, Manager, WOS)

Another manager whose department had split between working on site and working at home described how out of work communication within a department had contributed towards resentment of a shielding member of staff who was working entirely remotely:

> "*And other members of staff haven't been overly sympathetic to her circumstances […] then what's happening that they'd been off on bike rides. Now I know them. I know they're being very, very safe and they live in the middle of nowhere. But that sort of leads to a bit of: 'Well, she can go on a bike. Why can't she come in and, you know, do some work?' Yeah. So that's very tricky*." (027, Manager, MWL)

This tension was also expressed from the participants who were working remotely who perceived that other members of staff who did not understand, or who had forgotten, that remote working had been implemented according to a risk assessment in order to keep staff safe and prevent the spread of the virus; that it was a safety measure rather than a choice.

Concerns about reintegration

Reintegration of remote workers following the lockdown period was a significant concern for some participants. Many of these concerns were concerned with the practicalities of working after a period away from the office: diary entries detailed concerns about work which had piled up on site because it couldn't be carried out remotely, integrating workers into an office which was too small to support safe social distancing, or the practicality of using masks around the workplace. Other concerns pertained to team dynamics, particularly where an individual in a department had been working remotely for shielding purposes, though one participant discussed the long-term impact which they thought remote working would have on the workforce:

> "*I think that this is going to have a long-term effect once all this is finished and we do return to normal. This is going to cause a big divide in in a lot of areas within the Trust because you will be looking at your colleagues knowing that some you know that that they have worked a fraction of the time in which you worked […] the longer this goes on, the deeper the problems and the resentment is going to become*." (005, Clerk, WOS)

Disconnection within the hospital

Some participants also mentioned how the layout of the hospital contributed to physical disconnection between staff prior to the Covid-19 pandemic. The hospital site was described as being structured around a large, central corridor in the main hospital with some satellite buildings surrounding it. The corridor was referred to as a metaphorical heart of the hospital with a significant proportion of the workforce being either based on or regular users of the space. Even within their diary entries, participants discussed how the corridor was integrated into their working practice: how it acted as a point of contact and unity for staff, and how it often presented a focal point for communication between staff members. It was described as being significant that the measures for the virus, particularly home working and social distancing, had caused this foundation stone of the hospital to be removed, contributing to social disconnection within the hospital.

> "*No, the usual best source of communication is the "hospital corridor"! It's a shame that people are spread out now*." (016, Manager, WFH)

> “*And because we are part of a community and the generations of families that work here, I can see people are struggling with that. The corridor is a big conduit for a lot of conversations, it’s not now because you can’t stop because it’s not secure*.” (028, Director, MWL)

While the corridor, when regularly used, contributed towards connection within the hospital, other diary entries described how it historically also acted as a barrier or distancing factor, and how it contributed to them feeling disconnected from the rest of the hospital and influencing their decision making:

> “*Working the ARC has its advantages and disadvantages: The nature of the building means we are fairly isolated from the main hospital, but also we tend to get forgotten about when decisions are made, and communication is very ward/clinically based*.” (002, Manager, WOS)

> “*So and then I think I think [...] how much do you fight off other people? Do you function as a department or do you function as an organization? So I tend to want to defend our patch, we’ve had quite a lot of people wanting to use our rooms because we’re off the main corridor, a safe space, we’re potentially very clean so we could open the doors to other people coming in […] But the trouble is, once they come in, you can’t get rid of them. So on the whole, I’ve been chasing them off and growling at people at the door. But then you think, well, actually, is that is that a good way to manage things when you’ve got to consider the whole hospita*l?” (027, Manager, MWL)

Interestingly, the implementation of physical distance due to social distancing measures established similar responses from individuals in departments which previously had been linked to the corridor and connected hospital, leading to disconnection with some of the Covid-19 implementations:

> “*To be honest with you the wider hospital [from our perspective] doesn’t really affect us. We’re almost like a separate entity in the hospital at the moment because generally I don’t come off the ward other than to go to the office and for a meeting. Normally we would be on and off the ward getting our patients to and from the gym area but since lockdown we haven’t been able to use our gym.*” (014, Physiotherapist, WOS)

Though this was only observed in one participant and not exhibited consistently across the observational period.

9.5 Identity in relation to work role

Individual identity in relation to the situation and the organisational changes which had impacted on the hospital was also common in the diary entries. This was most commonly expressed through the development of stronger working relationships between the staff who worked on site throughout the observational period, or the development of group identity within the hospital, but some participants discussed individual identity changes in their diary entries.

Group identity changes

Camaraderie

One of the greatest personal developments observed in the diary entries were the improvements of staff relationships, and an increased awareness and empathy with other individuals. A strong camaraderie and positive staff relationships between staff was described by all of the participants who worked on site. Relationships between staff were described as being "strong", and "jolly" with "people working together in a way they don't normally".

Most participants expressed a feeling that they were supported by their colleagues: "people feel like they're there to help and support each other" and "offers of assistance [are] always made when needed", and this was present both inside and outside of work:

> "*There's certainly been a lot of solidarity staff. There's been a lot of helping each other out. You know, the WhatsApp group discussion last night was how to make masks and who's got elastic and that willing to share it around, you know, that kind of thing […] It's been great. People have been really. Really supportive.* "(027, Manager, MWL)

This camaraderie and willingness to provide help and support was also extended beyond their colleagues and was expressed as an increased awareness of the patients and the public:

> "*Does it change the way I think about things? Well I mean, yeah, I kind of, you put others first don't you, as you think that your actions probably, directly, going to impact on, on other people's health, so it's kind of, you put your own needs to the bottom of the pile, it's like I'd love to go to a garden centre and sort my garden out but I don't need to, it's not essential*, " (014, Physiotherapist, WOS)

Several of the participants who worked on site linked this to the fact that the wards were quieter, with fewer patients in the hospital due to the virus, which enabled them to spend more time with the patients and develop positive relationships with them.

Not only did participants discuss the increase in camaraderie and the genuine care that they perceived in their colleagues, but a great number also emphasised their want and need to help staff and others, their willingness to volunteer to undertake new or additional tasks from a position of supporting their colleagues through the difficult time. One described putting additional pressure on themselves to help others who were facing difficulties, while others discussed their concern and responsibility for the staff in their departments.

Several participants noted considerable developments in their departments during the Covid crisis. Descriptions of the departments prior to the onset of the virus, described how the department that they worked within had acted as a series of separate units according to their role within the department rather than as a group. The participants described how these divides had disappeared during the crisis and talked positively about how the department was beginning to function as a single unit again, with good levels of group morale and camaraderie.

Across all of the diary entries there was a strong sense of the workforce working together to ensure everyone was safe through the crisis and this was echoed in the participants' words:

> "*I've certainly felt really supported by my colleagues, in a way that probably I haven't felt at Oswestry for many, many years, it really feels that people are actually watching each other's backs and there to support you*" (009, Director, MWL)

There was hope that this would continue for the future, and that departments and the hospital as a whole would be cemented together by the experience,

Individual impact of camaraderie

Part of strong staff links and camaraderie was a personal feeling of appreciation and support. Appreciation was noted from the public, leadership, and members of staff around the hospital, one participant described how touched she was to have been recognised publicly on YouTube, and the positive, heart-warming feelings which accompanied it.

> "*They put a thank you on the YouTube channel for my help that I'd given to them and support and that was really, it was lovely, it was really nice, humbling. I don't*

> *do anything at all for thanks, I do it because I just want to be the best I can, [...] [I] just want to be able to give as much support and help to my colleagues and be the best that I can be for my patients. [...] but it was lovely, it was really kind and it really meant a lot*."(003, Team lead, WOS)

Some participants further discussed the impact that this had on staff wellbeing and identity within the organisation. The benefits they mentioned that staff appreciation brought to the team, ranged from supporting staff and reducing stress, to reducing feelings of isolation experienced as part of working from home, to building strong team bonds and improving morale:

> "*It's all very morale boosting and it really helps everybody within the Trust to keep on top of everything, um to make them feel important, to make them feel wanted, to make them feel that they're all part and parcel of a team, it's quite good to see.*" (019, Manager, WOS).

Personal development

As part of responding to the final series of prompts, a number of individuals discussed their own personal takings and developments from the lockdown and observation periods. A common desire was the opportunity "*use this period as a chance to reset*", or a chance to promote positive change. The comments about personal development largely looked forward to how the speakers wanted to adjust themselves to be in the future in light of their experiences during the pandemic, or actions that they had undertaken to start that process of change. Many of these comments discussed changes in priorities and desire to improve, ranging from having an increased appreciation of family and wanting to prioritise spending more time with them in the future, a desire to be less frustrated with people about work tasks in the future, or to have developed skills and crafts through the lockdown. One participant talked in detail about changing their lifelong mentality from a busy lifestyle full of activities, to an appreciation of the importance of valuing down time and rest Another participant articulated an increased awareness of the habits of the old ways of living, with an emphasis on unnecessary consumerism.

Although perceived personal developments were generally positive and promoted growth in the future, a number of staff reported some challenging personality changes and developments in other staff members which had occurred during the pandemic. Opportunities which arose as part of the lockdown process offered many the opportunity to take on new roles and responsibilities and in some cases this was reported as having a negative impact on employees. Participants recorded changes to people's personalities and the conflict which this incurred. In one department, a participant mentioned how a scarcity of opportunities caused their colleagues to change their personality:

> "*there was a bit of conflict between two registrars, [...] [over] cases which are considered gold dust operations. So it was interesting to see different interactions between colleagues, how - maybe because of the COVID situation, now operations have become [precious]- how people's personalities [...] have changed, they have changed a little bit more, bit more - don't know the word to be honest, bit more crafty I would say, manipulative*." (023, Doctor, WOS)

While another suggested that Covid-19 offered individuals an excuse to justify problematic behaviour:

> *"I think I just feel disappointed that, you know, people have used it, it almost seems to be an excuse for behaviour, it almost seems to be, you know, that, oh everybody's tired, everybody's stressed, everybody's worried, well they are, but, you know, we can't keep saying it's because of COVID that so and so's behaved like that or, you know, sometimes surely COVID or no COVID we, we have to take responsibility for our actions and our behaviours."* (003, Team lead, WOS)

And wrote in detail about how the excuses intensified existing problematic behaviour in their department.

9.6 Conclusions

The diary entries produced as part of this study presented the lives of a range of employees from across the hospital, all of whom had extremely varied experiences of the pandemic. There were, however, notable similarities and key central themes which emerged from the data mostly, as expected, revolving around the working environment which had changed significantly during the opening months of the pandemic, and four key themes were identified in the text.

Commonly discussed in the diary entries was the presence and development of disconnection, or boundaries, between the staff. These mostly surrounded the recently implemented remote working, but interestingly the diary entries also described pre-existing boundaries within the hospital site. The diary entries not only described the boundaries and the impact that this had on the staff, but also provided considerable insight into the factors which caused them to arise and be maintained or challenged. The changes of the pandemic, and the impact that they had on the emotions and the identities of the staff members, provide a broad understanding of context and the influencing factors which contributed towards the disconnection articulated by the participants, supporting a greater understanding the social, psychological, and cultural mechanisms which support the development and perpetuation of the boundaries in the workplace.

Chapter Ten: Discussion

10.1 Introduction

The initial period of the pandemic was a particularly intense and stressful time for everyone. In the participating hospital of this study, the organisational changes contributed to strain on staff, and every participant also discussed the wider impact that the pandemic played in their non-working life. Analysis of the diary entries highlighted the impact that external influences and context can have on both the personal identity of employees and the identity of an organisation as a whole and produced a broad base of information from which to investigate the experiences of the workforce.

The impact of the pandemic and the organisational changes implemented by the hospital was well documented within the data. The most notable impact was the emergence and development of two key boundaries within the hospital workforce: a social boundary, established between site-based workers and home based workers; and a symbolic boundary, observed between those who worked, and those who were perceived to not work throughout the pandemic. The participants in the study represented a wide range of positions and departments across the hospital, and this provided a number of perspectives from which to investigate the processes and mechanisms by which the social and symbolic boundaries were initiated and strengthened across the hospital.

Of the contributing factors which led to the emergence of the boundaries, context in particular was seen to be a key driving force: if the pandemic and associated governmental/organisational changes had not occurred, the hospital staff situation would likely not have changed. Context is already established as a factor which can play a significant role in the process of dissolving and developing boundaries (Meier, 2015). However it was not the only factor which led to the development of the social and symbolic boundaries within the workforce: a number of other mechanisms were identified which contributed to the process. Physical distance contributed towards the development of the social boundary, while three main categories of mechanism were identified as contributing to the emergence of the symbolic boundary: social, psychological, and cultural.

In this discussion, I present a model which discusses the context and mechanisms that contributed towards the development of the social and symbolic boundaries within the hospital. I discuss how the context: Covid-19 and the organisational changes which were implemented in response to the pandemic, acted as a catalyst for the formation of a social boundary between staff. I then move on to discuss the social, psychological, and cultural factors which acted as mechanisms to form and perpetuate the symbolic boundaries between staff, including those which emerged due to the context, and those which pre-existed within the hospital prior to the pandemic.

10.2 Social boundaries

Social boundaries are described as physical divides between individuals: situations where differences between groups of people are physically manifested, typically through access to some type of resource, whether that be physical or emotional (Lamont & Molnár, 2002). In this study, participants described a social boundary which had arisen between employees working in different locations, specifically between 'Home-based workers' and 'Site-based workers'. The development of this social boundary within the hospital was catalysed here almost entirely contextually, initiated by organisational change which occurred as a response to the pandemic, specifically the move to have a significant proportion of staff working remotely. The social boundary was initially established through physical distance between staff but was enhanced through restricted access to resources on site, and social opportunities.

Staff who worked from home were not only physically distanced from the hospital site, but many reported a reduction in opportunities for social interactions. Some remote staff members described an inability to access records or software that they needed to carry out their role which led to them being unable to carry out the same amount of work as they did on site.

> "*I will work from home on a Friday to help with social distancing but only have access to NHS mail*." (017, Admin, RH, MWL)

The choice to implement remote working had wider consequences beyond the implementation of a social boundary. Working from home also contributed to stress levels for home-workers, many of whom described the sudden transition to a new way of working as being very difficult. Some described the emotional difficulties of working from home, in particular the lack of ability to carry out casual conversation with colleagues. The ability to joke and complain with colleagues has already been established as a coping mechanism amongst hospital workers, supporting staff in what can be a taxing working environment (Pouthier, 2017). By reducing the opportunities for social interactions with colleagues for people working remotely the Trust inadvertently contributed to increased intensity surrounding work and removed a much-needed coping mechanism during a time of crisis. This was apparent in the diary entries. One participant who worked from home for the majority of their participation described increased pressure and stress associated with having to conduct meetings through Teams with little opportunity for casual conversation.

These feelings were notably alleviated once they were able to start to work back on site and talk to colleagues in person again.

> "*I did have some chance this afternoon to have some good, decent conversations with [my colleagues] and it was really nice just to sort of talk about how we are feeling, what things were coming along [...] and I think that is probably why I felt a lot better in the sense that there is a combination of having, you know, meetings, intense meetings, versus actually a chance to catch up and discuss in a more flexible sort of way what was important, what was going on. One of the problems I am finding at home is that it is just full on intense and no chance to sort of go talk things over a cup of coffee*." (009, Director, MWL)

In addition to the social impact of working remotely, the impact of working in a liminal situation, from both the pandemic and the temporary nature of the organisational changes, is also likely to affect the workforce (Turner, 1969; Borg & Soderlund, 2015). Introducing remote working hurriedly with no definite end data is likely to have contributed to additional stress amongst the staff (Beech, 2011), though this could be lesser in staff who had worked remotely before the pandemic. Most participants described experiencing additional stress during the observational period, though given that everyone was also affected by the pandemic and associated personal problems, it is not possible to determine the extent that remote working, and the social boundary which emerged because of it, affected the stress levels of the individuals.

Other social boundaries within the hospital

Working with physical distance between employees has also been shown to act as an ostracising factor within groups and can impact on working relationships within an organisation (Tempest & Starkey, 2004). While tensions within working relationships were mentioned by a couple of participants in this study, it was not possible to assess the wider impact of the social boundary on working relationships due to the relatively short observational period. However, a second social boundary was observed within the diary entries. Some participants alluded to a long-standing social boundary within the hospital which revolved around the physical layout of the Trust, and where people worked in relation to a central corridor in the main hospital, better defined as: 'Those who work in offices attached to the main corridor of the hospital, and Those who work away from the main corridor'. Staff discussed the impact of their department not being in the main building and their perception that being situated off the main corridor led to them being “forgotten about” in decision-making and communication processes (002, Manager, WOS).

This social boundary also contributed to the way the departments reacted during the pandemic, with one manager discussing how their position contributed to their decision-making during the early observational phases:

> “*So and then I think, how much do you fight off other people? Do you function as a department or do you function as an organization? So I tend to want to defend our patch, we’ve had quite a lot of people wanting to use our rooms because we’re off the main corridor, a safe space, we’re potentially very clean so we could open the doors to other people coming in […] But the trouble is, once they come in, you can’t get rid of them. So on the whole, I’ve been chasing them off and growling at people at the door. But then you think, well, actually, is that is that a good way to manage things when you’ve got to consider the whole hospital*?” (027, Manager, MWL)

While the development of social boundaries can be difficult to prevent organisationally, they can be problematic because they can impact on personal and organisational identity on an individual level and impact on working relationships between staff. This can promote the development of smaller social groups within the collective rather than a wider level of identity with the organisation as a whole which can, as shown above, impact the wider organisation, shaping the way that decision-making is made across the hospital, and the way relationships are formed.

10.3 Symbolic boundaries

In addition to the social boundary described above, the diary entries described the emergence of a symbolic boundary across the workforce. The boundary manifested between ‘People who continued to work during the pandemic’ and ‘Those who did not’, though many participants used a proxy of ‘Site-based workers’ and ‘Home-based workers’ when discussing this boundary in their entries. Like the development of the social boundary, context also played a significant role in the development of the symbolic boundary within the hospital. The Covid-19 pandemic and the lockdown policies and the consequential organisational change and policies which were implemented in the early months acted as a catalyst, prompting a number of actions and responses which worked in tandem and stimulated the establishment of a symbolic boundary. These contributing factors, or mechanisms, can be grouped into: cultural, social, and psychological mechanisms, and are discussed in greater detail below.

10.3.i Cultural mechanisms

The cultural mechanisms which contributed to the development of the symbolic boundary were all embedded within the culture of the hospital: its values and the attitudes that it held towards its workforce, and how staff interacted within that framework. The following key elements were observed to function as mechanisms which contributed towards the establishment of the symbolic boundary:

— ‘NHS heroes’: organisational identity and ingroup development

— NHS culture of “present-ism”

ʻNHS heroes’: organisational identity and ingroup development

A person’s wellbeing and behaviour are affected both by the attributes they ascribe to themselves and by those they believe others infer about them from their organisational membership (Dutton, Dukerich, Harquail, 1994). While working in a career and workplace, employees undertake identity alignment processes and developments to match their colleagues, environment, roles, expectations, knowledge associated with the roles, and the cultural traditions of the workplace (Giorgi & Palmisano, 2017; Brown, 2019) until the individual reaches a personal equilibrium with their environment. For some this also involves assimilating organisational identity with personal identity (Anteby, Chan & DiBenigno, 2016). The cultural narrative for the NHS and associated workforce is that it is made up of caring people who work hard to support the public with their illnesses. This is often assimilated into the organisational identity of employees, integrated with a personal identity to encourage individuals to present as a caring person who works hard to support the public. This cultural narrative was likely intensified during the early phases of the pandemic where there was a strong public emphasis on the NHS and appreciation for staff, particularly those on the front line, for the work that they were doing to support the country with the virus. The pandemic, and the increased presentation of NHS staff as ‘heroes’ who are essential for the public to survive Covid-19, potentially emphasises the organisational identity within the individual and increases the likelihood of them wanting to fit in with these ideals. The cultural narrative increased from being ‘caring people who work hard’ to ‘NHS heroes who work hard around the clock against adversity to save the nation from the virus’. This was further enhanced by the presentation of overworked hospitals, and staff working to burnout in the news. Together these put pressure on NHS staff to assimilate further with the new cultural narrative in order to return to equilibrium with personal and organisational identity.

Third parties have also been reported as being able to significantly influence the development of boundaries, despite not being physically involved in the boundary itself (Langley et al., 2019). In this situation, it is likely that the peer pressure applied by the public to reinforce the desired cultural narrative of NHS staff contributed to increasing the pressure for staff to comply with the organisational identity and contribute more towards supporting the country through the crisis. The employees, already having assimilated the cultural narrative of the NHS as part of their organisational identity, responded to enhanced cultural narrative by describing their willingness to work harder and more flexibly in order to support the hospital in a time of crisis:

> *"[...] not only myself but everybody who is turning in and whose face you see on a regular basis, they are all really really willing to step up to the mark and do their bit and they really do feel like that they're making a difference and helping out*." (005, Admin, WOS)

This affected relationships within the workforce in two key ways via enhanced camaraderie which dissolved some of the existing boundaries and the development of new symbolic boundaries.

For staff who were able to continue working on site and within or close to their employee role, the intensified organisational identity was beneficial. A number of participants reported increased camaraderie and strong working relationships within teams and departments, and many described willingness to adjust working hours or responsibilities to support the hospital as they dealt with the organisational changes which occurred as a result of the virus.

> "*There's a really good feeling at the moment in the hospital, [...] the camaraderie is very very good, people always stop and talk, people are very chatty, people smiling um it is a very much we're all in this together type thing*." (005, Admin, WOS).

This promoted a strong group mentality and contributed to both physical and emotional support throughout the pandemic, and contributed towards the establishment of a strong ingroup between staff who were working on site together: 'those who are working hard (in line with the cultural narrative) to help/support others in this crisis'. These are positive facets and worked successfully to support staff and the running of the hospital through a period of uncertainty.

Development of symbolic boundaries

However, the increased staff bonds also likely acted as a mechanism for the development of symbolic boundaries. While the promoted ingroup and high levels of camaraderie amongst staff provides a means to support them through a difficult time, the promotion of a strong ingroup with membership criteria based on culture led values, means that people who are unable to meet the criteria fall into an outgroup made up of people who do not meet the ingroup membership criteria. These underlying criteria can form the basis of symbolic boundaries and can potentially be damaging to the workforce as they cause division between the staff and cause difficulties in work and staff relationships, as seen in the diary entries–and additional stress and perception of victimisation in the people unable to meet the ingroup criteria. The development of staff groups also contributes towards the development of a symbolic boundary between them, a line which clearly distinguishes one from the other and maintains the integrity of the groups.

The assimilation with the enhanced cultural narrative was not ubiquitous, however, and also contributed to tension and feelings of negativity within members of staff who were perceived to be part of the ingroup but who did not consider themselves to meet the membership criteria. While adherence to ideals associated with the culture of the organisation positively impacted on the workforce, this pressure to act in a particular way to be an “NHS Hero”, to be on the front line fighting Covid-19 and protecting patients, also potentially raised feelings of guilt within perceived ingroup members (i.e. those who were working on site and continuing to work through the pandemic, but who were no longer seeing patients due to cancelled services). Discrepancies between the perception of what they were doing versus what they perceived that they should be doing could potentially impact on the wellbeing of staff. Although not explicitly discussed in the diary entries, feelings of guilt were anecdotally described among staff who felt that they were not able to meet the expectations of NHS staff during the pandemic, and were not experiencing the same pressures or difficulties which were presented on the news and which resulted in the supportive gestures offered nationwide to NHS workers.

NHS culture of “present-ism”

A small number of participants discussed their experiences with remote or flexible working in the hospital, and the restrictive approach that the NHS and the Trust held towards allowing staff to work from different locations. Some staff members described not being offered the opportunity to work at home, while another explained that remote working had previously not been offered to many staff because of the underlying NHS culture which perceived remote workers to not be as productive as those who work on site.

> "*So the NHS may have been a traditional giant of present-ism: you're only productive if you are here*." (028, Director, mixed)

As a long established, underlying belief within NHS work culture, this is also likely to influence the general perception that people working at home are not working and feed into the thoughts of the employees working on site.

10.3.ii Social mechanisms

Two key social mechanisms supported the development of the symbolic boundary:

- — The social boundary within the hospital
- — Othering

Social boundary

The social boundary established in the hospital was a significant driving point for the development of a symbolic boundary, in particular the physical distance between the two groups and shift from physical to virtual meetings. This impacted on the relationships within the hospital. Remote working has already been observed to challenge the relationships and established dynamics of a workplace (DiDomenico, Daniel, & Nunan, 2014), while lack of contact and casual bonding through physical distance has also been described as contributing to distortion of staff relationships (Lervik et al., 2010; Swart & Kinnie, 2014). Similarly working in a liminal situation has also been suggested to act as an ostracising factor in a workforce and contribute towards poor working relationships across the organisation (Tempest & Starkey, 2004). The social boundary created through increased physical distance and inability to continue normal social relationships, enhanced by restricted communication between staff and increased tension across the workforce, led to the formation of the symbolic boundary and the development of two distinct social groups. It is also likely that this clear distinction contributed to the use of the proxy 'site-based workers' and 'remote/home-based workers' when discussing the symbolic boundary.

Othering

The boundary between the two groups ('People who continued to work during the pandemic' and 'Those who did not') was expressed and maintained narratively within the data, by merit of the participants expressing themselves through diary entries. However, these expressions also offered insight into the means by which the symbolic boundary was perpetuated within the organisation.

A number of participants exhibited ‘othering’ within their entries, discursively emphasising the differences between the two groups by contrasting their behaviours through stigma or shame (Turner, 2007). Many of these descriptions used direct contrast between the two sides of the symbolic boundary, clearly situating the speaker as a member of the ingroup with associated social identity attributes, and marginalising those who are not working as members of an outgroup (Tajfel & Turner, 1979).

> *“...not only myself but everybody who is turning in and whose face you see on a regular basis, they are all really really willing to step up to the mark and do their bit […] but how other people are getting away with not actually working, not working at all some people, or being given days off in between time is wrong*.” (005, Clerk, WOS)

Most people who discussed the boundary used clear language like this to describe the two groups and the differences between them, marginalising people who were not able to work and establishing a clear boundary and ingroup/outgroup membership criteria. Even where comments were benign and non-judgemental about home working staff, they contributed to the perpetuation of the symbolic boundary. One manager said that they did not ask staff what work they were doing at home because they did not want to know if they weren’t doing any work, and while there was no negativity associated with staff being unable to work (due to them not having access to necessary resources) the comment reinforces the stereotype that many home workers were unable to work and contributes to marginalisation across the workforce (Barton, 2007) by reinforcing the others’ perception.

Previous authors have stated that members of marginalised communities often cope with the emotional impact of group membership by positioning themselves away from the negative connotations of group membership. This is done using two methods: distancing the self from outgroup membership by emphasising problematic outgroup traits with other marginalised group members, and by establishing secondary boundaries within the group (Barton, 2007; Copes, 2016). Elements of this were also observed in the diary entries in this study. Some individuals, perceived to be part of the minority/out-group by working at home, complained about the generalisation that home-workers were not working by emphasising that they were continuing to work hard.

> *“[...] some are suggesting that we’re sitting at home. I’ll give today as an example, I’ve been logged on since 7:30 and I’m still working at 6 and haven’t finished yet*.” (016, Admin manager, WFH)

Although the symbolic boundary, like the social boundary, appeared to be between staff working on site, and those who were working remotely, most of the comments referred to individuals' propensity to work, and was countered (as in the quote above) by comments referring to the amount of work carried out by home-workers. This emphasised that the boundary was between people who were working through the pandemic and those who were perceived as not working, rather than being about the location.

All othering, even that presented by other marginalised individuals, can be damaging to a workplace environment as it further perpetuates the presence of the out-group and the stereotypes associated with it, contributing to enhancing a boundary, making it more divisive and damaging (Barton, 2007). In the case of this study, this othering and sharing of negative stereotypes associated with out-group membership was allowed to perpetuate and cause emotional strain to remote workers and was described as introducing tension between working relationships.

There were also some comments which worked to dispel the symbolic boundary. While uncommon, these comments directly tackled the assumptions underlying the symbolic boundary: that people working from home were not working and did not conform with the cultural identity of the NHS, by emphasising elements where remote-working staff dispelled the assumptions which had been placed upon them. Some comments emphasised staff members' lack of choice regarding location of work and the reason why they were working remotely, and in some cases their want to support their colleagues and work:

> "*One who's shielding because she's very vulnerable and she's working from home [...] and another member of staff is at home because her partner is shielding and we've decided that it's safer for her to be away. And she's found it hard in terms of guilt, really, about what she's not able to do* [...]" (027, Manager, MWL)

While another discussed wanting to implement measures to emphasise the work that home-based workers were carrying out despite the difficulties they were facing at home.

> "*I have come up with an idea today that in our comms to staff, that we are going to look at, not only talking about people who are doing amazing things in the hospital, but actually talking about what it's like to work from home under huge pressure as well, and thinking about doing something, something entitled 'Heroes at home', or something like that, with a positive focus on what they are doing*." (009, Director, MWL)

Positively dispelling the traits which formed the stereotype underlying the symbolic boundary could contribute towards dismantling the boundary between staff. By preventing the perpetuation of the ingroup/outgroup concepts in favour of a wider appreciation of the efforts of the workforce as a whole, comments like the above could shift the boundary to include all employees as 'staff working to support the hospital' and remove the tension within the organisation. Unfortunately, however, this process of dismantling or adjusting the boundaries could not be investigated as the observation period of this study meant that only the formation of the boundaries could be observed.

10.3.iii Psychological mechanisms

Psychological mechanisms which contributed towards the development of symbolic boundaries typically revolved around the high levels of stress and burnout which were affecting the workforce during the observation period.

The Covid-19 crisis was a global pandemic and constituted a super wicked problem within the UK, affecting those in the NHS more than many others. Covid-19, as a super wicked problem, caused the participants in the study to be affected by a wide range of elements during the observational period. Feelings of stress and angst, common in people experiencing crises (Brooks et al., 2015; Kornberger, Lexicering & Meyer, 2019), were regularly mentioned by the participants in relation to the organisational changes which occurred in the hospital; as were anxiety, confusion and uncertainty, which are characteristic of people working in liminal phases or locations (Beech, 2011), similar to the implemented remote working. A number of staff also described symptoms of burnout throughout their entries as they discussed stress associated with the new ways of working, and stress linked with guilt from staff members who felt that they were unable to meet their requirements associated with organisational identity.

Crises, liminal situations, stress, and significant change to an individual, like the organisational changes which occurred during this study, can lead an individual to undertake significant identity work to adapt to the new situation and maintain a positive internal identity (Tempest & Starkey, 2004; Ybema, 2010). Indeed, a number of individuals discussed how their identity had been affected by the pandemic or the impact of the pandemic on them, and how they perceived that it would shape their identity in the future. While this identity work is undertaken to support the individual and promote their equilibrium within the situation in which they reside, it can affect the way that they behave and interact with their working environment and potentially impact upon the relationships that they support within their life. Organisations are made up of complex interrelating units and are held together and supported in functioning by the social and relational bonds between staff (Currie & Brown, 2013). Stress, whether personal or organisational, and identity work can apply strain to these bonds, increasing the risk of damaging the relationships, and the likelihood of symbolic boundaries developing and continuing.

10.4 Conclusions

One of the most significant elements to have emerged during the observation period were the social and symbolic boundaries as a result of the Covid-19 pandemic, and the organisational changes and uncertainty which emerged in response. The pandemic directly contributed to increased stress levels and burnout amongst the hospital staff and strengthened staff identification as NHS workers, while the organisational changes incorporated into the hospital as a result of the pandemic led to the development of a social boundary between staff working on site and those working at home. These factors, combined with the underlying culture of 'present-ism' within the NHS contributed towards the development of a symbolic boundary between people who were working through the pandemic, and those who were perceived to be not working, though this was often discussed through a proxy of site-based workers and remote workers. Othering was also evident in the diary entries and was both introduced by the presence of the symbolic boundary and served to perpetuate the boundary within the staff. These mechanisms, and the interactions between them, have been visualised in image 4:

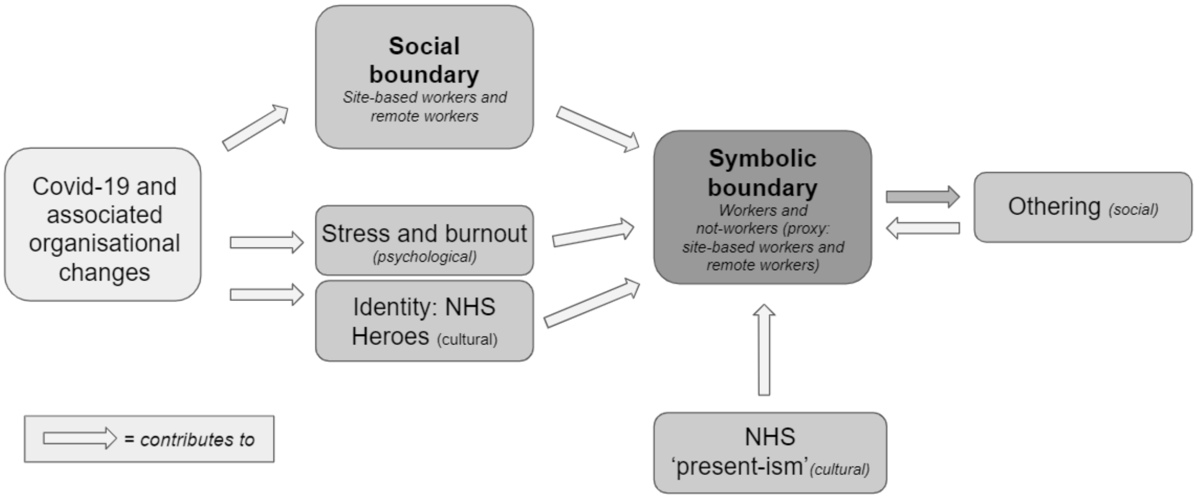


Diagram 4: Factors and mechanisms which contributed towards the development of the social and symbolic boundaries amongst the hospital staff.

Social and symbolic boundaries can have a significant impact on workforce and staff, affecting working relationships and contributing to shifts in the organisational culture. As both the social and symbolic boundaries were catalysed by context: the pandemic and associated organisational changes, these findings highlight the impact that organisational change can have on a workforce.

Organisations function productively through the relationships between staff (Currie & Brown, 2013). Where boundaries emerge within the workforce they produce rifts and divisions within the institution which can infringe on the organisation's ability to work effectively both in the present and the future. By studying the mechanisms and factors which influence employees' behaviour and the development and perpetuation of boundaries between staff, it is possible to identify boundary development as it emerges in a workforce. Understanding the interactions which lead to the production of boundaries means that measures can be taken to prevent boundaries taking hold and impacting the organisation, and allows organisations to undertake work to break down those boundaries and better support their staff in the future.

10.5 Limitations of the study

Although the diary entries collected during the observation period provide a reasonable perspective of the hospital through the lockdown period, there were limitations involved with the study. A relatively short observational period, and inconsistency across participants' diary entries, in length, subject matter, and the periods over which they reported, meant that it was difficult to see the development of the boundaries in detail or whether it was perpetuated long term. The freedom of participants to provide diary entries of their own length, and at any point across a prolonged period of time, and ability to drop out whenever, meant that relatively few reported their experiences over the majority of the observation period, and that there were a range of times covered in the entries themselves–those which were written early in the observation window described very different experiences to those who reported in the later phases. Similarly, not being able to follow up with the participants about the boundaries or ask more detailed questions about their experiences also led to a shallow view of the phenomena.

A greater number of participants and a longer observational period would have provided a better data set to draw conclusions from, however, Due to the nature of the period in which the observations took place, and the additional stresses that the healthcare staff were under, there was little that could be done to improve the number of participants or the extent that the participants produced diary entries, as it was important to minimise the toll that the study had on the participants who were already working under extremely stressful conditions. Although it limited the depth at which we could investigate the social and symbolic boundaries within the workforce, the participants who took part in the study still presented a wide view of the phenomena and allowed a detailed analysis to take part.

10.6 Future research

It has become increasingly apparent that the Covid-19 pandemic will not be short-lived and will continue to impact the country in the future, notably the continuation of social distancing and some elements of working from home. Even beyond this, the social and psychological impacts of a period of crisis and change may continue to affect how people behave. This will continue to impact on the social elements of the NHS, notably the support systems which employees rely on daily. To successfully manage workplaces post Covid-19, organisations will have to make significant changes to their policies and practices. In particular, there will be a need for a strong understanding of the stress and disruption that everyone has faced, and a greater flexibility handling employees' needs (Shaw et al., 2020). Understanding the behaviours and social interactions within the workforce, and the mechanisms by which they emerge, is key to developing beneficial policies and practices in an organisation. Future research could continue to monitor Trusts within the NHS to investigate the long-term social and psychological impacts of the pandemic (Holmes et al., 2020). This would realise the full impact of the virus and support the NHS in establishing a robust system to assist their employees in periods of difficulty in the future.

Chapter Eleven: Conclusions

This thesis set out to determine the value that qualitative investigations can bring to healthcare environments through the investigation of the experiences of patients and staff. While the first phase of the project was not completed, it emphasised the need for a better understanding of the factors which influence patient compliance and developed a series of research methods for younger participants to thoroughly investigate compliance qualitatively and quantitatively. The second phase of the project collected diary entries of the experiences of healthcare staff during the pandemic and used these to gain insight into how staff responded to organisational change. Through the diary entries, it was possible to not only identify the presence of the boundaries but also some of the factors and mechanisms which caused them to develop and perpetuated them.

While qualitative research methods can be time intensive and require large amounts of input from the participants, the projects within this thesis and the other studies carried out during this MPhil period (see Appendix 19 for publications of this work) has found them to be effective in producing rich, insightful data. In particular, the diary entries allowed a wide range of staff to participate on their own terms and engage with their own subjects of interest. While prompts were given to stimulate and guide responses, a number of individuals talked enthusiastically about different topics which interested them or which they found relevant -one in particular talked in detail about the impact the pandemic had on their family dynamics- and it was this freedom for them to discuss anything that they thought important which contributed towards the richness of the data. It was the richness of the data which enabled the mechanisms supporting the development of the boundaries to be identified. These benefits do not, however, undermine the beneficial work that quantitative and other qualitative methods carry out. This project merely seeks to highlight the benefits of using qualitative research methods for studying experience and observes the insight that this can bring to healthcare research. Each research method is a specific tool which produces a particular output and is relevant for its own specialist area, none is better or worse than the other. As seen in the first phase, often a mixed methodological approach offers the most insightful means to investigate a particular phenomenon.

People's responses to their experiences are not restricted to the locations in which events occur, they are carried with them as they go about their lives. Medical treatment, particularly devices which are visible to others, and organisational changes do not just impact the receiver in the target location but will have wider implications for the individual as they interact with other elements of their life (context). Over time this could lead to non-compliance, or a poor working environment. By taking the time to listen to people and explore these experiences in a holistic way, it is possible to gain a greater understanding of the interacting factors and mechanisms which influence the behaviours and responses to the situation, even those which aren’t immediately obvious to the casual observer. This knowledge provides the insight which can act as solid foundations for the implementation of successful wider organisational change or amendments to medical treatments which are designed to meet the specific needs and expectations of the people who use them. These findings support more detailed qualitative research being carried out in the future to support medical device and organisational change development and implementation in healthcare organisations.

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List of Appendices

Part One: Experiences and perceptions of AFOs

Part Two: Experiences and perceptions of health care workers during the Covid-19 Pandemic

Appendix 1–IRAS favourable ethical opinion. Reference: 265723

NHS
Health Research
Authority

West Midlands - Solihull Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0207 104 8019

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

02 December 2019

Dr C Stewart
Senior Research Fellow, Keele University and Clinical Engineer RJAH Orthopaedic Hospital Keele University/RJAH Orthopaedic Hospital
ORLAU
RJAH Orthopaedic Hospital
Oswestry. Shropshire
SY10 7AG

Dear Dr Stewart

Study title: Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs) using quantitative measurement of function and qualitative evaluation of experience and wellbeing
REC reference: 19/WM/0305
Protocol number: N/A
IRAS project ID: 265723

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair. **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy
volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*	
Interview schedules or topic guides for participants [AFOs in CP Interview Schedule and Topic Guide]	1,1	25 September 2019	
IRAS Application Form [IRAS_Form_20092019]		20 September 2019	
IRAS Checklist XML [Checklist_29102019]		29 October 2019	
Other [Response to REC]		28 October 2019	
Participant consent form [Parent's consent form]	2.1	28 October 2019	
Participant consent form [Child's Assent Form]	2.1	28 October 2019	
Participant information sheet (PIS) [Child's Information Sheet]	v 21	28 October 2019	
Participant information sheet (PIS) [Parent's information sheet]	2.1	28 October 2019	
Research protocol or project proposal [Protocol]	1.2	21 August 2019	
Summary CV for Chief Investigator (CI) [CV of Chief Investigator]		29 August 2019	
Summary CV for student [CV for Student]		30 August 2019	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating

Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving research/learning/

19/WM/0305 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely

PP: Dr Rex J Polson
Chair

Email: NRESCommittee.WestMidlands-Solihull@nhs.net

Copy to: Dr Caroline Stewart

Appendix 2– FMHS REC favourable ethical opinion. Reference: MH-190066

Keele University FMHS Faculty Research Ethics Committee
health.ethics@keele.ac.uk

23 October 2019

Dear Alice,

Project Title:	Understanding the factors affecting compliance in children with cerebral palsy using Ankle Foot Orthoses (AFOs) using qualitative evaluation of experience and wellbeing and quantitative measurement of function
REC Project Reference:	MH-190066
Type of Application	Main application

Keele University's Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS FREC) reviewed the above project application.

Favourable Ethical opinion
The members of the Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the start of the project.

	Required changes
1.	**Data protection and confidentiality**

	i. The compliance of the study with University Data Protection Policies must be clarified. The link to this policy is: https://www.keele.ac.uk/media/keeleuniversity/sas/governancedocs/policiesandprocedures/DP%20Policy_v1.8.pdf For example, in Section 7.3 of the Ethics form, it must be clear that the storage of the assent / consent forms and identifiable keys are stored separately and with separate passwords to the raw data. ii. It was not clear to the panel how the issue of confidentiality in the focus groups would be managed. What measures will be put in place to address how this data is handled and how the issue of confidentiality in this context is managed? iii. How will the applicants ensure that a child with cerebral palsy or other conditions with motor deficits will not be one of the children in the focus groups? In the absence of such screening it was felt that there is greater potential for upset from the discussions that would take place. Screening for participation in the focus groups should therefore be clarified (following on from this, have the applicants considered how perceptions may vary if the children have a sibling, family member or friend with an AFO or similar condition?) Please provide responses to the above points to the FMHS FREC via health.ethics@keele.ac.uk.
2.	**Consent form and patient information sheet** It is not clear if anonymous quotes are to be used. This should be clarified by the inclusion of an additional statement to reflect this in the consent forms.
	Recommended changes
1.	It needs to be clarified if there is an intended comparison of primary and secondary school responses in the focus groups, or if group data is to be amalgamated?

Reporting requirements
The University's standard operating procedures give detailed guidance on reporting requirements for studies with a favourable opinion including:

- Notifying substantial amendments
- Notifying issues which may have an impact upon ethical opinion of the study
- Progress reports

- Notifying the end of the study

Approved documents
The documents reviewed and approved are:

Document	**Version**	**Date**
All documents submitted with MH-190066	-	19 Sep 2019

Yours sincerely,

Dr Gary Moss
Chair

Ethics [Health] <health.ethics@keele.ac.uk> (sent by d.goddin@keele.ac.uk)

Wed, 13 Nov 2019, 15:32

Dear Alice,

Many thanks for providing these updated documents in response to the conditions of your Ethical Opinion. These conditions have now been satisfied, and your application has a Favourable Ethical Opinion.

Best wishes,

Dave

Keele University FMHS Faculty Research Ethics Committee
health.ethics@keele.ac.uk

02 March 2020

Dear Alice,

Project Title:	Understanding the factors affecting compliance in children with cerebral palsy using Ankle Foot Orthoses (AFOs) using qualitative evaluation of experience and wellbeing and quantitative measurement of function
REC Project Reference:	MH-190066
Type of Application	Amendment
Amendment Reference:	MH-20012
Amendment Date:	30 January 2020

Keele University’s Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS FREC) reviewed the above amendment.

Favourable Ethical opinion
The members of the Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met prior to the implementation of the amendment.

1.	None.

Reporting requirements

The University's standard operating procedures give detailed guidance on reporting requirements for studies with a favourable opinion including:

- Notifying substantial amendments
- Notifying issues which may have an impact upon ethical opinion of the study
- Progress reports
- Notifying the end of the study

Approved documents

The documents reviewed and approved are:

Document	Version	Date
All documents submitted with MH-200112	-	30 Jan 2020

Yours sincerely,

Dr Gary Moss
Chair

Appendix 3–AFO designs offered to children in an NHS Trust


Limb spot Transfers
Incredibles Spot
Spiderman Spot
Shield Spot
Ironman Spot
Batman Spot
Spiderman 2 Spot
Hulk Spot
Captain Spot

Appendix 4–Participant information sheets and consent forms

Parent information sheet (Projects A, B, C)

Orthotic Research and Locomotor
Assessment Unit,
RJAH Orthopaedic Hospital,
Oswestry,
Shropshire,
SY10 7AG

01691 404532

Study Number: RL1796

REC Number: 19/WM/0305

INFORMATION SHEET

Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs)

using quantitative measurement of function and qualitative evaluation of experience and wellbeing

Name of Researchers: **Miss Alice Faux-Nightingale and Dr Caroline Stewart**

We are really pleased you and your child are interested in helping us with our research.

Please ask if there is anything you don't understand or anything else you would like to know.

- ***Why are we looking for children to take part?***

Our department is called ORLAU and is part of the Orthopaedic Hospital. We measure and treat lots of children who have problems with walking, running or moving about. Lots of children are given Ankle Foot Orthoses to wear (called AFOs).

We know AFOs can help children to walk better, but they are not always popular with our patients. Children often wear their AFOs less as they get older, particularly when they go to secondary school. We have an idea why this is. Secondary schools are much bigger, so it can be harder to get around. Children also start to feel more self-conscious around adolescence. Whilst we think this is the case we don't know for sure so we would like to invite some children to help us explore the issues in more detail.

- ***Why do we think your child could join in?***

We are interested in working with children with cerebral palsy in the upper end of primary school (years 5 and 6) or the lower end of secondary school (years 7 and 8). Our clinical team think your child may be suitable because they use AFOs and are in mainstream school.

We also need children to be able to walk well enough to do the tests we have in mind, including a ‘gait assessment’.

- ***What will they have to do?***

Alice, our researcher from Keele University, would like to follow your child over a few weeks (3-6 months in total). At the start we will do a gait assessment in ORLAU to measure what the AFOs are doing. There is more detail about that below. We will also put a small sensor into one of their AFOs and that will allow us to monitor when they wear them and for how long. At the end of the trial period Alice will talk to your child about how they feel about their AFOs. She will also collect some information from you

.

The sensor which goes into the AFOs is very small so your child shouldn’t notice it at all. It will record when during the week they use the AFO. We can download the data when you come and see us. Don’t worry, your child won’t be in trouble if they don’t wear their AFOs as much as they should. We just want to know if they wear it more at school or at home, during the week or in the evenings and at weekends.

We will do the gait assessment with your child wearing their AFOs and again walking without them. For the assessment we will record data with our special tracking cameras and also take video film. We can do both assessments in a single visit of 1-2 hours. Your child may have had a gait assessment before, but if not it’s quite a simple test. They will need to walk in our laboratory wearing small reflective markers attached to their legs. There are pictures on the front page to show you what it looks like. We do gait assessments very regularly and they are completely safe.

For the gait assessment your child will need to wear shorts and a T shirt or crop top. They can bring their own clothes with them. One of our doctors or physiotherapists will do a simple clinical examination of their legs. They will also put little dots on their skin with a pen to help our measurements. We do need to stick things on to your child’s skin with sticky tape. Sometimes taking it off can be a bit uncomfortable, a bit like taking off a plaster. We can let children take things off themselves if they want to.

Lastly, we want to talk to your child. Alice will invite your child to come and talk about their experience of using AFOs. Alice will need to record the conversation and take video film so she doesn’t miss anything and doesn’t have to take notes. She will let you and your child see her summary report afterwards so you can check you are happy with it. You will be in the same room as your child during the interview. You will be able to keep an eye on what's going on but we're interested in hearing directly from your child. You will also have another job to do at the same time as Alice would like to collect some comments and feedback from you. She will provide a paper pack for you to do that.

- ***Does my child have to be a volunteer?***

No, it's entirely up to you and your child whether to volunteer. If you think they might like to then you will need to come and see Alice. She'll be able to tell you more about it and help you to make the final decision whether to go ahead. Even after we've started your child can change their mind, and we will stop any testing or recording. We won't ask them to tell us why they've changed their mind.

- ***What do we get from taking part?***

Hopefully you'll enjoy helping with our research. We'll show you and your child lots of technology and can show your child how they move on our computers if they would like to see.

Our overall aim is to improve children's experience of using AFOs in the future.

- ***Who will have access to my child's data and information?***

Because your child is one of our patients we keep records about them in our hospital notes and electronic records. This is known as 'identifiable patient information' because people who access that information can tell who your child is. Only the clinical team in ORLAU will have access to your child's identifiable patient information until you agree to take part. After that Alice will also have access so she can look at the historical information about your child's walking and AFO. She will also need to contact you about appointments.

If you agree to take part in the research Alice will collect more information, for example the gait assessment data and interview recordings. Both of these will contain video film and it will be possible to recognise your child from the video. All the video will be stored on NHS computers then archived indefinitely, as part of their NHS record. Alice will also process the data on NHS computers to create transcripts, measurements and graphs. The processed data will be electronic files and they will be given a code number so it will no longer be possible to identify your child (the technical term is pseudonymised data). Once that has happened the files will be copied to a university computer for further analysis. It will not be possible to identify your child in any reports or publications based on their data.

There are laws about how we can use your child's data (The General Data Protection Regulation (GDPR) and the Data Protection Act). We will give you a general document which explains how research data is used and stored. If you have any further questions please do let us know.

When you come and see us we will explain all that's involved to you and your child. You'll be able to ask us all the questions you want to before deciding whether or not to join in.

The research we are doing has been approved as safe by a panel of experts known as an Ethics Committee. This research was approved by the Solihull Research Ethics Committee.

If you would like to contact someone who is not on the research team who can give you independent advice please speak to the Patient Advice and Liaison Service (PALS). You can also contact them if you have a concern or complaint to raise.
You can phone PALS on 01691 404606, email rjah.pals.office@nhs.net or write to the address below.
Patient Experience Manager / PALS Lead
Robert Jones & Agnes Hunt Orthopaedic Hospital NHS Foundation Trust,
Oswestry, Shropshire, SY10 7AG

Parent consent form (A,B,C)

Orthotic Research and Locomotor
Assessment Unit,
RJAH Orthopaedic Hospital,
Oswestry,
Shropshire,
SY10 7AG

01691 404532

Study Number: RL1796

REC Number: 19/WM/0305

Patient Identification Number for this trial:

CONSENT FORM FOR PARENTS/GUARDIANS

Title of Project: **Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs) using quantitative measurement of function and qualitative evaluation of experience and wellbeing**

Name of Researchers: **Miss Alice Faux-Nightingale and Dr Caroline Stewart**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated October 2019 (version 2.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason, without their medical care or legal rights being affected. ☐
3. I agree to ORLAU storing information about my child (including any photographs or video taken during the assessment and video/audio recordings of the interview). ☐
4. I understand that my child's data may be published in research reports and papers. I give my consent so long as they cannot be recognised or identified in publications. ☐
5. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my child's records. ☐
6. I agree that my child can take part in the above study. ☐

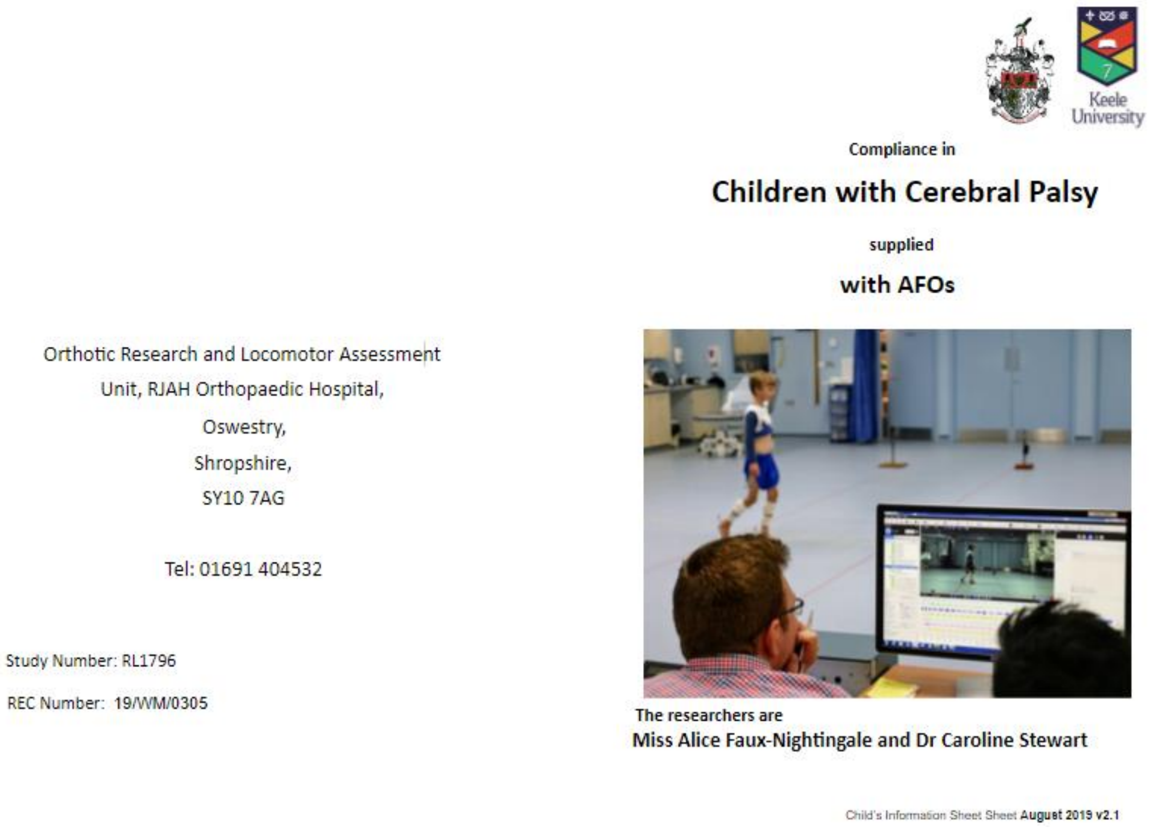
Name of Participant

Name of Parent/Guardian Date Signature

Name of Person taking consent. Date Signature

Copy for parent/guardian, copy for site file, copy for clinical record

Child information sheet (A,B,C)



Compliance in

Children with Cerebral Palsy

supplied

with AFOs

Orthotic Research and Locomotor Assessment
Unit, RJAH Orthopaedic Hospital,
Oswestry,
Shropshire,
SY10 7AG

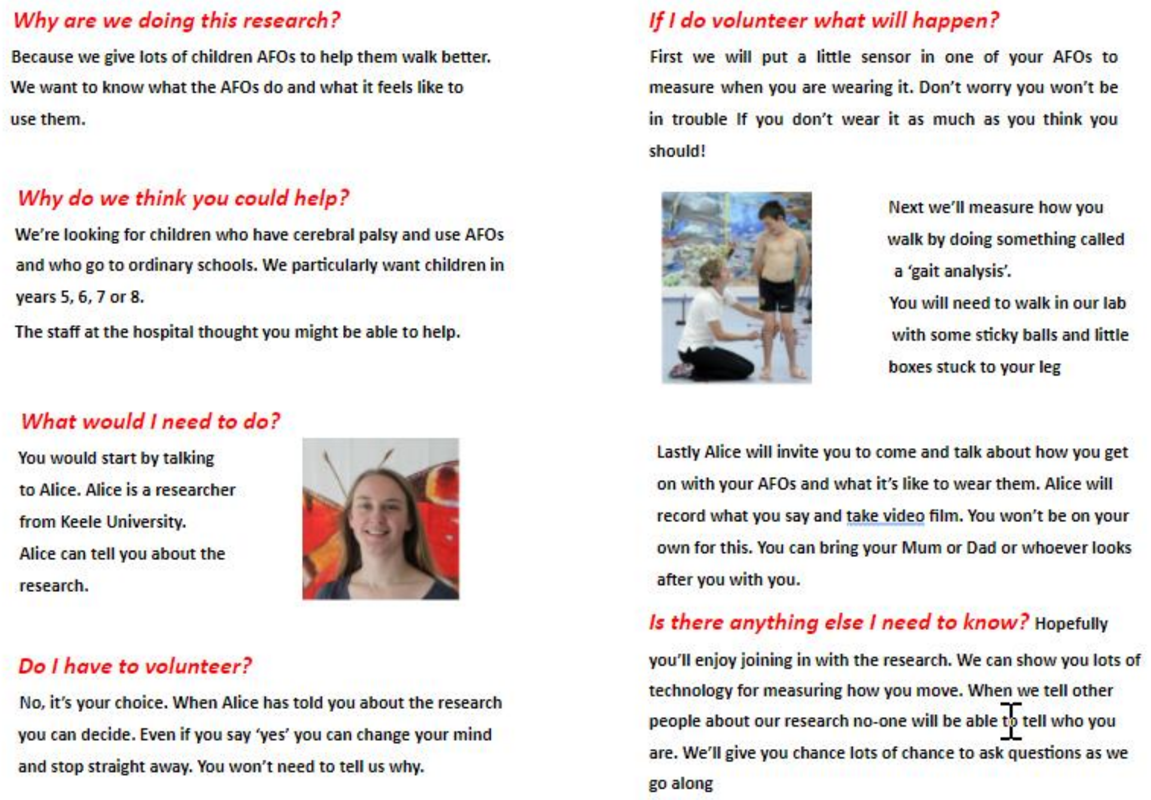
Tel: 01691 404532

Study Number: RL1796

REC Number: 19/WM/0305

The researchers are
Miss Alice Faux-Nightingale and Dr Caroline Stewart

Child's Information Sheet Sheet **August 2019 v2.1**



Why are we doing this research?

Because we give lots of children AFOs to help them walk better. We want to know what the AFOs do and what it feels like to use them.

Why do we think you could help?

We're looking for children who have cerebral palsy and use AFOs and who go to ordinary schools. We particularly want children in years 5, 6, 7 or 8.

The staff at the hospital thought you might be able to help.

What would I need to do?

You would start by talking to Alice. Alice is a researcher from Keele University.
Alice can tell you about the research.

Do I have to volunteer?

No, it's your choice. When Alice has told you about the research you can decide. Even if you say 'yes' you can change your mind and stop straight away. You won't need to tell us why.

If I do volunteer what will happen?

First we will put a little sensor in one of your AFOs to measure when you are wearing it. Don't worry you won't be in trouble If you don't wear it as much as you think you should!

Next we'll measure how you walk by doing something called a 'gait analysis'.
You will need to walk in our lab with some sticky balls and little boxes stuck to your leg

Lastly Alice will invite you to come and talk about how you get on with your AFOs and what it's like to wear them. Alice will record what you say and take video film. You won't be on your own for this. You can bring your Mum or Dad or whoever looks after you with you.

Is there anything else I need to know? Hopefully you'll enjoy joining in with the research. We can show you lots of technology for measuring how you move. When we tell other people about our research no-one will be able to tell who you are. We'll give you chance lots of chance to ask questions as we go along

---

Child assent form (A,B,C)

Orthotic Research and Locomotor
Assessment Unit,
RJAH Orthopaedic Hospital,
Oswestry,
Shropshire,
SY10 7AG

01691 404532

Study Number: RL1796

REC Number: 19/WM/0305

Patient Identification Number for this trial:

ASSENT FORM FOR CHILDREN

Title of Project: **Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs) using quantitative measurement of function and qualitative evaluation of experience and wellbeing**

Name of Researchers: **Miss Alice Faux-Nightingale and Dr Caroline Stewart**

Please initial all boxes

1. I have read the Information Sheet, or had it read to me, and I have asked any questions I want to ask. I know I can ask more at any point and know who to talk to if I want any more information. ☐
2. I know that I don't have to take part in this research and that I can stop whenever I want to, without having to explain why. ☐
3. I am happy for ORLAU to keep information about me, including photographs and video film. ☐
4. I agree to ORLAU using and publishing my data so long as no-one will be able to tell who I am. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

Copy for child, copy for site file, copy for clinical record

Parent information sheet (Project D)

Version 1: 03/08/2019

Information Sheet

Invitation

You are being invited to consider taking part in the research study:

Compliance in children with cerebral palsy

Researcher: Alice Faux-Nightingale

Aims of the research

This project seeks to understand the factors affecting compliance in children with cerebral palsy who are using assistive devices to help with their walking, with the hope that we can develop ways to reduce the negative social impact of assistive device use.

Children with cerebral palsy are frequently supplied with splints (otherwise known as Ankle Foot Orthoses) to aid their walking, these are made of plastic and come up to the knee. We know they can help children to walk better and can keep them active as they grow. Adolescence, notably the transition between primary and secondary school, is a difficult period and many children stop using their splints or use them less often which can lead to a reduction in mobility. There are huge benefits to patients in staying physically active into adulthood but this becomes more challenging if children are not using the splints which support them in their movement. We're carrying out research to try and identify the reasons why children stop using their splints in the hope that we can develop ways to improve usage and acceptance.

The session that your child will take part in will provide us with a broader context for the project and allow us to understand the perception of the children's peer groups. We hope this research will help clinicians manage patients better and also inform changes in splint design.

We will be carrying out schools sessions in primary secondary schools, interviewing children with cerebral palsy and their families, and carrying out clinical analyses of their walking to try and understand why and when children use their splints. We hope this research will help us make splint use more acceptable for children, and as such help them improve their mobility and independence.

Why has my child been invited? Do they have to take part?

Your child has been selected because they are in year 5, 6, 7, or 8 and do not have any motor difficulties. As such, they provide a view of how peer groups perceive walking problems and assistive devices such as splints, and their opinions should help us develop ways to improve the social acceptability of the devices and increase their use during adolescence.

Your child does not have to take part and should only do so if they, themselves, would like to. Please take some time to discuss this project with them and ensure that they understand the information on this sheet before they decide whether or not they join in.

What will happen if my child takes part? How will their information be used?

If your child chooses to take part, they will attend a creative, discussion based activity, approximately an hour long, which will encourage them to think about walking and to share their opinions about children with cerebral palsy and the devices they use to help them move around.

The session will be video and audio recorded, according to preference. I will use the recording to produce a transcript of the session and will analyse the points of discussion as part of the study. Your child's information will be kept anonymous at all points following the recording: no real names or identifying information will be included in the transcripts, images, clips, or descriptions of data which are used in reports, presentations, or other methods of dissemination.

Who will have access to the information gathered from the sessions?

During the study, all data will be stored on a password protected, encrypted laptop which can only be accessed by me. The raw data, i.e. the audio or video footage, will not be shared with anyone and will only be seen by myself and my direct supervisors. I will make an anonymised transcription of the raw data, ensuring that nothing can be traced to the children who took part, and this will be used during the analysis and where the study is disseminated in anyway, e.g. a report or presentation. The data will be destroyed after 5 years.

Whilst everything said in the meetings will be treated as confidential, I have to work within the confines of current legislation over such matters as privacy and confidentiality, data protection and human rights, and so offers of confidentiality may sometimes be overridden by law. For example, in circumstances whereby there is concern over any actual or potential harm to the participating children, I must pass the information over to the project supervisor who may then pass it on to other relevant authorities.

What if there is a problem?

This study poses little psychological or physical risk for the participants and will abide by ethical procedures specified by Keele University. However, the children involved are free to leave the study at any point without giving a reason why.

If you have a concern about any aspect of this study, you may wish to talk to me and I will do my best to answer your questions (Alice Faux-Nightingale - a.faux-nightingale@keele.ac.uk). Alternatively, you may contact my supervisor, Dr Caroline Stewart - c.stewart@keele.ac.uk.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the Research Integrity team at Keele on research.governance@keele.ac.uk.

Parent consent form (D)

Version 2: 25/10/2019

Parental consent form

Project: Compliance in children with cerebral palsy

Researcher: Alice Faux-Nightingale

Name: ....

Name of child: ....

Child’s age: .... Child’s gender: ....

Child’s year group: ....

Please tick if relevant:
[ ] My child has cerebral palsy or uses AFOs

[ ] My child lives with a family member who has cerebral palsy or who use assistive devices to help them walk.

Please initial all boxes.

[ ] I confirm that I have read and understand the information sheet (Version 1, dated 03/08/2019) for the above study. I have had the opportunity to raise any questions and have had them answered. I know who to contact if I have any further questions in the future.

[ ] I understand that my child does not have to do this and can say no at any point. I understand that I can withdraw their data at any point without giving any reason.

[ ] I agree that my child can, if they so wish, take part in the study and the session.

[ ] I agree to my child being audio recorded.

[ ] I agree to my child being video recorded - all data will be fully anonymised before being shared with any parties outside of the research group and no-one will be able to link them to the project.

[ ] I understand that my child’s comments may be published in any reports or papers as part of the project. If this happens, all comments will be anonymised and will not be linked to my child.

Signed: .... Date: ....

For the researcher to fill in:

School: ....

Name: Alice Faux-Nightingale

Signed: .... Date: ....

Child information sheet (D)

Version 1: 03/08/2019

Participant Information Sheet

Invitation

You are being invited to consider taking part in the research study:

Compliance in children with cerebral palsy

Researcher: Alice Faux-Nightingale

My name is Alice and I'm part of a research team at Keele University. We're doing some research about children with disabilities and how they are viewed by the people they go to school with.

Why am I being asked to join in? Do I have to?

You have been selected because you are in year 5, 6, 7, or 8.

You don't have to take part and should only sign the assent form if you would like to join in with the session. Make sure you take all of the forms home to your parents or guardians and talk to them about the project so that everyone knows what you will be doing. You won't be able to take part if you don't have a signed consent form from them too.

What will happen if I take part? How will my information be used?

If you choose to take part, you will take part in an hour long activity session, which will find out what you and other people in your class think about walking and children with disabilities.

The session will be video and audio recorded. I will use the recording as part of my research but I won’t let anyone else see the images or know that you are involved. When I write about the project or tell people in presentations, I will change everyone’s name to something new and make sure that there is no way for anyone to know that you were there or what you said.

Who will have access to what we say in the session?

During the study, all of the data will be stored on a laptop which can only be accessed by me. The videos of our session will not be shared with anyone. I will write out a script of everything that we say and I will change everyone’s names and anything that you say that could identify you. The script with false names is the script I will use when I write my report or presentations. All of the information I have from the session will be completely destroyed after 5 years.

All of the things we discuss in the meeting will be confidential which means I will not tell anyone what you said in the session unless someone is in danger, in which case I might have to tell your teacher or the person who is helping me with the project.

What if there is a problem or if I’m not sure?

If you have any questions or worries about the session then you can either talk to me or ask your teacher or parent/guardian to email me. They can get in touch with me (Alice) at a.faux-nightingale@keele.ac.uk.

Don’t forget that if you are very worried about this project, you don’t have to take part. No-one will be cross or disappointed if you don’t want to join in.

Child assent form (D)

Assent form:

Cerebral Palsy Study - School Visit

Project: Compliance in children with cerebral palsy

Researcher: Alice Faux-Nightingale

Name: ....

Age: .... Gender: ....

Year group: ....

Please tick if relevant:
[ ] I have cerebral palsy or use AFOs

[ ] I live with a family member who has cerebral palsy or who uses equipment to help them walk.

Please initial all boxes

[ ] I have read the information sheet or had it read to me, and I understand that I will take part in a session about disability. I understand that I do not have to do this and can say no at any point.

[ ] I have asked any questions I want to ask and understand the project. I know I can ask more at any point and know who to talk to if I want any more information.

[ ] I agree to be audio recorded

[ ] I agree to be video recorded - all data will be anonymised and no-one will be able to link me to the project.

[ ] I agree to take part in this project.

[ ] I understand that where my quotes are printed from this session, they will be anonymised so that no-one can tell that they came from me.

If you do not want to take part, do not sign this form.

Signed: .... Date: ....

For the researcher to fill in:

School: ....

Name: Alice Faux-Nightingale Signed: ....

Date: ....

Appendix 5–Interview schedule

Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs) using quantitative measurement of function and qualitative evaluation of experience and wellbeing

Researcher: Alice Faux-Nightingale

Plan for hospital interviews

Aim for session: to discuss experiences of living with CP and using assistive devices, particularly within their school environment (primary/secondary)

Broad understanding of individual experiences and perspectives of AFOs and reasons for compliance.

Semi-structured interview, led by the participant's conversation - questions may change slightly or not get asked according to how the participant responds.

Session Plan

Room layout: Containing a large table that the interviewer and interviewee can sit around, with space also for parents to be carrying out a separate activity.

While child is participating in the interview, parents will be given an activity to engage with. This will serve three purposes: to collect information from parents of children with CP and AFOs about their child's experiences of living and using assistive devices, it provides a means to support or verify the comments made by the children, and should reduce the amount that parents contribute to the interview, allowing the children to lead the discussion and talk about what they feel is relevant.

- **Introduction - Establish rapport, introduction to the interview. (5 mins)**

- **Perspectives of AFOs (15mins)**
  - **Tell me about your AFO. Describe it.**
  - **What do you think about it?**
  - **How does it feel? How does your walking feel with/without it?**
  - **<u>Using the diagram of a person with an AFO and the emotion stickers.</u> Which bits do you like/not like? Why?**
  - **What's it like living with an AFO?**

- **Experiences of living with CP and using assistive devices (15mins)**
  - **<u>Using the map and the emotion stickers.</u> Where do you like to spend time? Where do you wear your AFO? Where do you go by yourself/ with your family?**
  - **What's it like having CP?**

    - **How does CP and having an AFO impact on your life?**

- **Experiences of living with CP/using AFOs at school (15mins)**
    - **Tell me what it's like at school.**
        - **What's it like having CP at school?**
        - **What's it like having AFOs at school?**
        - **(If in secondary school, how is this different from primary school?)**
        - **What would you like your friends and classmates to know about CP/AFOs?**

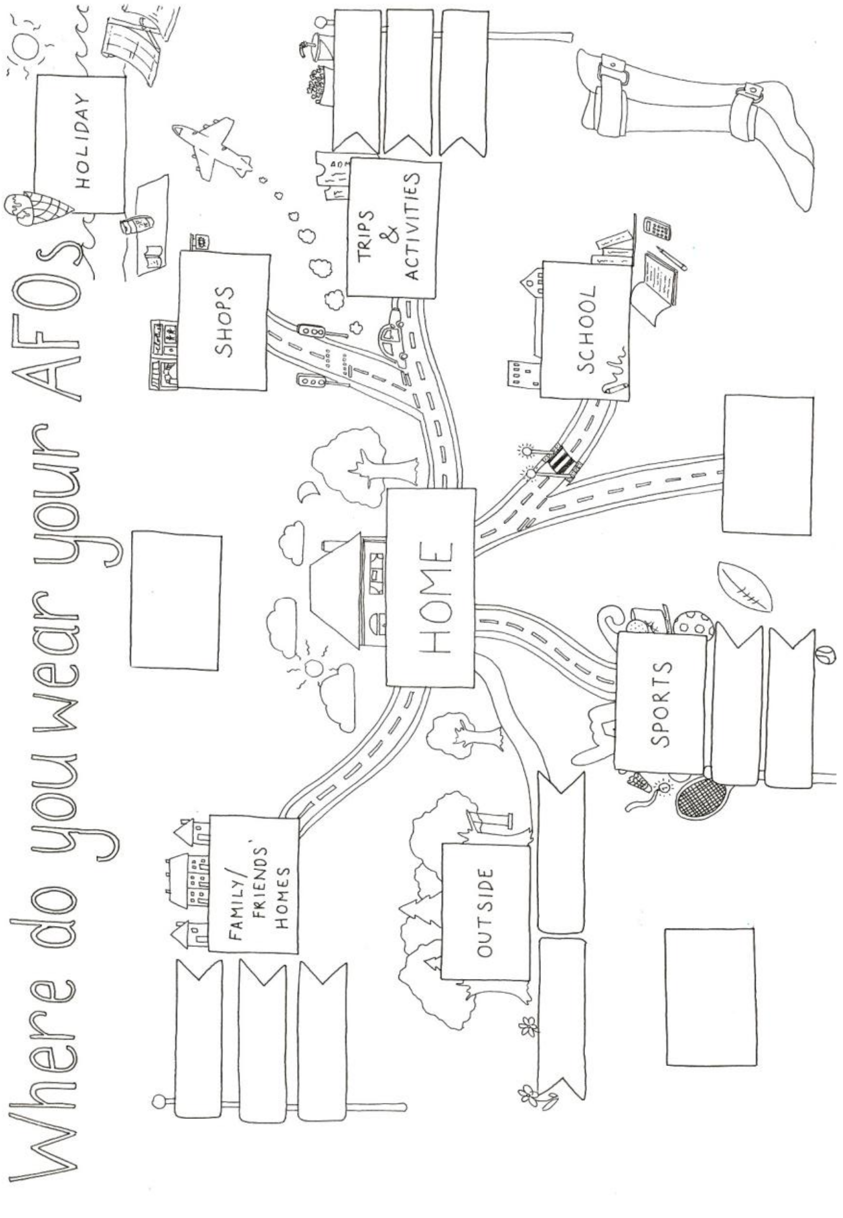
- **Round up (5mins)**

5minutes left unallocated to allow for further discussion at any point.

If run under time, possible questions:

- **What do you think teachers need to know before someone with CP/AFOs start in their class?**
- **What would you tell someone who has just been given an AFO?**
- **What do you think people think about your AFO?**

Appendix 6–Participant worksheet



Appendix 7–Emoji stickers

Appendix 8–Dinosaur sticker

Appendix 9–Parent work pack

Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs) using quantitative measurement of function and qualitative evaluation of experience and wellbeing

Researcher: Alice Faux-Nightingale

Plan for activity

Aim for session: to collect information from parents of children with CP & AFOs about their child's experiences of living and using assistive devices while their child is being interviewed. Activity also acts as a means of reducing the amount that parents input into the interview and disrupt from what the child is saying, and provides a means to verify the comments made by the child.

Equipment: Folder containing: one information sheet (below), one map, one diagram of a child wearing an AFO, postit notes, emotion stickers, and pens.

Understanding the factors affecting compliance in children with cerebral palsy supplied with Ankle Foot Orthoses (AFOs) using quantitative measurement of function and qualitative evaluation of experience and wellbeing

Researcher: Alice Faux-Nightingale

<u>Interview: Parents' activity</u>

It is important that the information gathered from this interview is from your child, and that the experiences and perspectives that they share are entirely their own. Hence, if you could refrain from making any additions or corrections to your child's comments during the interview, it would be appreciated. If you feel that there is something essential that has been omitted, or if you would like me to be aware of any additional information, there are post-it notes in this folder that you can use for anything you think is relevant. If your comment is too long to add to a postit note, please write on the back of this sheet or on the spare paper provided in the folder.

Enclosed in this pack are: a map of the local area where you live, a diagram of an AFO user, emotion stickers, post-it notes, spare paper, and pens. I would appreciate it if, while your child is being interviewed, you would complete the following activities:

- **Map - Using the emotion stickers, pens and post-it notes, please highlight:**
    - **Where your child wears their AFO (if there are significant locations not present on the map, please write these - e.g. "Grandma's House"- on a postit note and place around the outside of the sheet.**
    - **Any significant emotional responses to key locations. E.g. Places that they**

    enjoy being or feel secure, or places where they are nervous or significantly unhappy.

  - **Any locations that are notably inclusive or positive for AFO use, and any locations that are difficult to navigate with an AFO or which have negative connotations.**

- **Diagram of an AFO user - Using the emotion stickers, pens, and post-it notes, please highlight your child's response to their AFO: areas that they like or don't like and whether or not it impacts on their body image.**

Any additional comments or insights that you may have are welcome, please feel free to add as much or as little as you like to any of these documents. Thank you.

Appendix 10–Letter to school

Version 2.0 Jan-2020

Initial email to school - primary and secondary

Project: Compliance in children with cerebral palsy

Researcher: Alice Faux-Nightingale

Dear [Headteacher],

My name is Alice. I'm currently working on a research project at Keele University and I wondered if your school would be willing to help. I'm interested in children's views of disability, particularly the use of walking aids and walking of children with cerebral palsy, and have put together a fun, activity-based workshop session to talk to children and help them think through issues of disability. Do you think that you might have some children who would be willing to join in with this? All data about the children or school would be entirely anonymous in any published report, and the children will be free to opt out at any point. Do you think that is something your school would be willing to help with? If so, I can send a more formal request with full details, but I would be very happy to come in and talk through the project with you or one of your staff. I am DBS checked and have lots of experience working with children and devising engaging workshops.

Thank you for your help.

Alice Faux-Nightingale

Appendix 11–Follow up letter to school

Version 2.0 Jan-2020

Follow up email to school - primary and secondary

Project: Compliance in children with cerebral palsy
Researcher: Alice Faux-Nightingale

Dear [Headteacher],

My name is Alice Faux-Nightingale and I'm currently working on a research project with Keele University. We are running an investigation into the factors that affect orthosis use by children with cerebral palsy, focusing on the transition between primary and secondary school.

Children with cerebral palsy are frequently supplied with Ankle Foot Orthoses (or splints) which support their walking and keep them active as they grow. Our study seeks to investigate the use and perception of splints by children with cerebral palsy from a variety of angles to gain a better understanding of the factors influencing children's compliance. We hope to use the project as a whole to identify ways that we can support the use of splints, hopefully increasing patients' independence and wellbeing.

As part of this study, we would like to find out how walking styles and splints are viewed by able bodied children who don't have cerebral palsy. This will provide us with useful context for the entire study and will allow us to see how children with cerebral palsy experience educational environments and their peer groups on a day to day basis. To investigate the views of children without cerebral palsy, we would like to go into two schools (one primary, one secondary school) and carry out a focus group with a small number of children. The session is a very low risk activity which will ask participants to discuss the splints and walking patterns associated with cerebral palsy.

I will need the school to be able to provide:

- A means for us to recruit approximately ten children from year five or six. I have information sheets, consent forms and assent forms, but I need an opportunity to recruit. ● A one and a half hour slot for me to conduct the focus group. Ideally within the school day, and as soon as possible.

- A room to carry out the focus group in. This needs to be big enough for a group of 10-12 (including staff) to sit in a group and have enough space for children to move around in. I will need a large table for everyone to sit around and ideally a projector, although I can adjust the session if these facilities are not available.
- A member of staff to sit in on the session while it runs. The member of staff should be someone who is unlikely to influence what the children discuss or how they respond to the topic.

Version 2.0 Jan-2020

Participation is entirely on a voluntary basis. The pupils will only be able to take part if they and their parents are willing, and will be given an opportunity to opt out at any point during the session without punishment or penalty. All data will be anonymised (pseudonymised), securely stored, and there will be no reference to either the children or the school in any published materials. I am DBS certified, and the focus group plan has been given a favourable ethical opinion by the Faculty of Medicine and Health Sciences at Keele University.

We're hoping to use this project to positively impact on the lives of children with cerebral palsy. If there's anything you can do to help, or you know any schools who would be willing to help, that would be appreciated. I am happy to meet and discuss the project or provide further information about the activities planned for the focus group if needed.

Do let me know if there's anything else that you might want.

Appendix 12 - Focus group presentation

Presentation:
https://docs.google.com/presentation/d/1bNpnn4RKMnBkbpNrRqUWueKjLy9PkXIiDK82ZUUgXv4/edit?usp=sharing

Appendix 13–Researchers' Epistemology

Written before research began - 17th and 23rd October 2019

I'm writing my thoughts and feelings and, i guess my basic understanding of the project now before I start to undertake the literature review or get stuck into planning. I'm 25, female, background in biology and psychology which included some work about "deviant" behaviours but didn't cover any psychology of long term health conditions etc. While I understand the basic biology of cerebral palsy, I don't know a lot more about it at this point other than from watching a couple of Youtube videos.

So… key things I think for me?

Limited experience with people with CP

I'm trying to think of situations where I might have met someone with CP before. I've done some work experience at ORLAU seeing the gait analysis process which almost certainly featured me watching children with CP be assessed but I wouldn't have had any verbal contact. There was a child with CP in the school that I used to work at, she was in a wheelchair and was very articulate and chatty with friends whenever I saw her, but I didn't have any direct contact myself. I know that we were told that we might have to tell her to slow down because she loved zooming around in her wheelchair - like most other children given an electric wheelchair, I'm sure. I also used to go to school with someone who used AFOs, possibly might have had CP, but I wasn't in many of her classes so I didn't know her very well. She seemed really nice though, we used to walk to school the same way.

Limited prior knowledge of CP

Outside of the textbook description, i know very little about CP, or what it's like to live with it. I've watched a few Youtube videos to try and prepare? There's a great standup comedian with CP that I found, and there was a TV series which followed a (fictional) man with CP as he moved out of his parents' and started an internship. I know these don't necessarily represent the kind of people I'll be working with but I think it gives me a bit of context?

AFOs

I've also got limited experiences with AFOs other than an acquaintance at school and watching a gait analysis session with AFO users. I've seen lots of pictures of them but I don't use them and with little exception have never required an assistive device to walk or carry out daily functions.

As someone who doesn't have cerebral palsy or any physical/mental disability, the prospect of being limited in some of the activities that i take for granted atm would be really difficult for me, and I am able to prioritise aesthetic appeal over function for a lot of devices/clothes/pieces of equipment because i have that range available to me. I think a big thing that I'll need to be aware of is making sure that I recognise that my experiences and priorities will be completely different to those of the people who participate in the study and I will need to make sure that I am careful to not let my experiences influence my interview questions and analysis.

Appendix 14–Clinical Audit Proposal Form

Project No.
Click here to enter text.

The Robert Jones and Agnes Hunt Orthopaedic Hospital
NHS Foundation Trust

Clinical Audit Proposal Form

Audit Title:	Experience of staff at RJAH responding to Covid-19		
Audit Lead(s) / Designation	Caroline Stewart (ORLAU manager/clinical scientist)		
Contact details	Caroline.stewart9@nhs.net Ext 4666		
Directorate / Service / Ward / Department	ORLAU. Specialist Services Unit		
Start Date	17/4/2020	**Estimated Finish Date**	1/10/2020

Background / Rationale to the Audit
(a brief history to the audit)

The Trust is currently going through a period of unprecedented change, affecting all routine services and staff roles. The changes to processes will be captured in documentation, minutes, emails and official communications. We know, however, that the crisis is affecting staff's experience of working life. How well we navigate the changes and uncertainties will depend on human factors. It is this human experience we are seeking to collect and analyse to ensure that it becomes part of the organisation's memory and a repository for learning.

Aim / Objectives
(Overall purpose of the audit - e.g. improve, enhance, ensure, change, obtain)

We plan to ask a group of staff to record daily audio diaries over a 3 week period. We hope to recruit up to 20 volunteers from across the organisation. We will seek volunteers through Trust communications and the staff Facebook group. Each volunteer will complete a simple Enrolment Form (see attached).

Each volunteer will be asked to record a 5 minute reflection at the end of each working day, submitting it via email. A prompt sheet will be provided to guide the reflection, focussing on positive as well as more challenging aspects of the day (see attached for initial prompts). The audio recordings will be transcribed for further analysis. The initial data collection will last for 3 weeks, with the prompts changing once a week in response to the emerging themes. We would like to repeat the exercise in the future when the circumstances change significantly.

To analyse the transcripts we will use standard methodologies developed in the social sciences, specifically thematic analysis. This will prevent those collecting and collating information from introducing personal bias and ensure the results are robust. The findings which will be anonymised will be collated into a report to be submitted to the Trust executive team.

The overall purpose is to understand what helps and hinders staff thriving through a time of crisis. This will help the Trust provide better support now and will also influence future training and planning.

Stakeholders and Their Involvement

	Involvement *(Tick as many as apply)*				
	Design	Data Source	Review Findings	Plan Action	Other
RJAH Clinical Staff	☒	☒	☒	☒	☐
Social Science Academics (Keele/Nottingham)	☒	☐	☒	☐	☐
RJAH senior managers	☐	☐	☒	☒	☐
Click here to enter text.	☐	☐	☐	☐	☐
Click here to enter text.	☐	☐	☐	☐	☐

What is the rationale for the audit taking place? What are the project drivers?			
Area 1 – External Must Do’s			
Care Quality Commission (CQC) Outcome*	☐	New national target	☐
Commissioning requirements and CQUINS	☐	NHSLA Standard**	☐
National Clinical Audit and Patient Outcome Programme (NCPOP)	☐	NICE	☐
National Patient Surveys	☐	Department of Health Requirement	☐
Area 2 – Internal Must Do’s			
Assurance Framework	☐	Organisational Clinical Issues	☐
Clinical Risk Issue	☐	Patient involvement projects	☐
Confidential Enquiries	☐	Risk Register	☐
Complaints & PALS	☐	Serious Untoward Incidents / adverse incidents	☐
Area 3 – Directorate Priorities			
Local Audit agreed as directorate priority	☒	Locally adopted clinical standards benchmarking e.g. Essence of Care	☐
National Audit (not part of NCAPOP)	☐		
Area 4 – Clinician Interest			
Individual interest	☐		
Reaudit *(please tick)*	☐	Title of original audit	Click here to enter text.

Other (please state)	This work is being carried out in response to an unprecedented period of change in the organisation
*Care Quality Commission – Essential Standards of Quality & Safety (if project is linked to a CQC Outcome please state which Outcome)	Click here to enter text.
**NHSLA Standard Details (if project is linked to NHSLA state which Criteria & Standard)	Click here to enter text.

Standards				
(It is important that we are able to demonstrate how our services compare against any available national best practice and guidance. Please note support from library services is available if required) Please attach appropriate documentation to this proposal form to evidence your standards				
No.	**Criteria**	**Standard** *(% compliance)*	**Exception(s)**	**Definitions and instructions for data collection**
1	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
2	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
3	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
4	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
5	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
6	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
7	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
8	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
9	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.
10	Click here to enter text.	Click here to enter text.	Click here to enter text.	Click here to enter text.

Method						
Will the project be……….	Retrospective ☐		Prospective☒			
How will cases be selected	Staff are being asked to volunteer					
From what time period will cases be drawn from?	April to September 2020 (initially)					
What is the target sample size?	At least 20 staff but in reality as many as possible					
Is the target sample size…….	All cases within a specified time period ☐ A sample of them ☒					
Data Source	EPR	☐	Questionnaire / Pro forma	☐	Database / Spreadsheet	☐
Other (please specify)	Volunteers' diaries					

Work Plan					
	By Whom	Planned Date		By Whom	Planned Date
Start Date	Caroline Stewart	17/04/2020	**Report written**	Team as above	31/10/2020
Data collected by	Caroline Stewart	30/09/2020	**Action plan agreed & completed**	Team as above	31/10/2020
Findings reviewed by	Caroline Stewart Karen Edwards Kerry Robinson Alice Faux-Nightingale Mihaela Kelemen	30/09/2020	**Report submitted**	Caroline Stewart	31/10/2020

Support required from Clinical Audit /Outcomes Department					
None	☐	Assistance with data collection	☐	Assistance with report	☐
Questionnaire / Audit tool	☐	Analysis of data	☒	Assistance with presentation	☐
Other (please specify) Help from Dr Claire McKechnie-Mason would be very useful given her expertise.					

Commitment and Support (for Clinical Audits)	
I agree to take responsibility for ensuring that the project is completed, reported and an action plan is devised to implant recommendations arising from the audit.	
Signature of person taking responsibility	Caroline Stewart
Print Name	Caroline Stewart

Date	21/05/2020
This has been agreed with the clinical audit lead for the speciality:	
Signature of Clinical Audit Lead	Click here to enter text.
Print Name	Click here to enter text.
Date	Click here to enter a date.

Appendix 15–Retrospective IRAS favourable opinion. Reference: 286648

Dr Caroline Stewart
Clinical Scientist/Manager RJAH, Senior
Research Fellow Keele University
Robert Jones and Agnes Hunt Orthopaedic
Hospital ORLAU
Oswestry
SY10 7AG

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

21 September 2020

Dear Dr Stewart

Study title: Experience of staff at RJAH responding to Covid-19 IRAS project ID: 286648

Protocol number: N/A

REC reference: 20/PR/0432

Sponsor Robert Jones and Agnes Hunt Orthopaedic Hospital

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.
Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *“After HRA Approval – guidance for sponsors and investigators”* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **286648**. Please quote this on all correspondence.

Yours sincerely,

Kathryn Davies

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: Miss Teresa Jones, Robert Jones and Agnes Hunt Orthopaedic Hospital

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
IRAS Application Form [IRAS_Form_25082020]		25 August 2020
Participant information sheet (PIS) [RJAH Staff experience of responding to Covid-19 Information Sheet and Enrolment form v1]	v1	17 April 2020
Participant information sheet (PIS) [RJAH Staff experience of responding to Covid-19 Prompt Questions v1]	v1	17 April 2020
Participant information sheet (PIS) [RJAH Staff experience of responding to Covid-19 Prompt Questions Week 2 v1]	v1	20 May 2020
Participant information sheet (PIS) [RJAH Staff experience of responding to Covid-19 Prompt Questions Week 3 v1]	v1	12 June 2020
Research protocol or project proposal [RJAH Staff experience of responding to Covid-19 Proposal v1]	v1	17 April 2020
Summary CV for Chief Investigator (CI) [IRAS CV CS. 2019]	v1	06 August 2019
Summary CV for student [IRAS CV AFN. 2019]	v1	12 August 2019

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	**Expectations related to confirmation of capacity and capability**	**Agreement to be used**	**Funding arrangements**	**Oversight expectations**	**HR Good Practice Resource Pack expectations**
This is a single site study sponsored by the participating NHS organisation therefore there is only one site type.	This is a single site study sponsored by the participating NHS organisation. You should work with your sponsor R&D office to make arrangements to set up the study.	This is a single site study sponsored by the participating NHS organisation therefore no agreements are expected.	No external study funding has been sought.	A Principal Investigator should be appointed at the study site.	The sponsor has confirmed that local staff in the participating organisation who have a contractual relationship with the organisation will undertake the expected activities internally. Therefore no honorary research contracts or letters of access are expected for this study.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 16–Participant information sheet and consent form

Experience of staff at RJAH responding to Covid-19
Information sheet and consent form

The Trust is currently going through a period of unprecedented change, affecting all routine services and staff roles. We need to learn from this experience to plan for the future. Changes to processes will be captured in documentation, minutes, emails and official communications but we know, however, that the crisis is affecting staff's experience of working life. We hope to explore these experiences through audio diaries to allow us to inform future planning and develop better staff training for the future.

If I take part, what will I have to do?

We would like you to produce a daily audio diary over a 3 week period. At the end of each working day we would like you to record a 5 minute reflection about your day using a prompt sheet that we will provide. This will ask about the events which occur during your day, both the positive and the more challenging aspects, but will also give you opportunities to talk about how the current situation is impacting you, and anything else which you think is important. Once you've finished, just send the audio file in an email to us.

Who is going to have access to my audio file? How will my data be protected?

Kerry Robinson is the executive sponsor for the project and Caroline Stewart (*ORLAU Manager)* will oversee the work at RJAH. Caroline will receive your audio files and arrange for them to be transcribed and anonymised, and pass on the anonymised transcripts to the academic partners for analysis. She will ensure that your entries are stored safely and confidentially. Although Caroline will handle the files, she will not listen to any of the entries and will only see the transcripts once they have been anonymised.

Karen Edwards will oversee the transcription process, and the anonymised data will be passed to Prof Mihaela Kelemen (Nottingham University) and Alice Faux-Nightingale (a Keele postgraduate student) who will carry out an analysis on the anonymised data and will work with the rest of the team to produce a report. All participants will receive a copy.

Data will be kept confidential at all points of the analysis process. However, if what you say reveals a situation which is potentially illegal or dangerous, we may have to break that confidentiality. In that unlikely situation, we will get in touch with you first to discuss how to proceed.

What will this project do? How will it help me?

This project is designed to capture how the experience of working through the pandemic is affecting Trust staff. We hope to gain an understanding of what helps staff to thrive and what reduces stress and hope to use this to inform future planning and staff training.

Do I have to take part?

No, this is an entirely voluntary study. If you do choose to take part, you are under no pressure to submit your diary entries. If at any point you feel that you are too busy or too tired to record an entry do not feel that you have to produce a recording then. You can comment on multiple days in later entries if it is easier for you to do so.
You are free to pull out of the study at any point and without an explanation. If you wish to do so, please email Caroline at **caroline.stewart9@nhs.net**, who will update our files.

Experience of staff at RJAH responding to Covid-19 – Enrolment form

Name: ………………………………………………………………… Gender:……………………………… Age:……………

Professional group:	
Pay band:	
Normal work role:	
Period of time spent working in a healthcare environment:	
Current Covid-19 work role:	
Current work location: *e.g. working from home*	
Current family situation:	

<u>Please put a cross in each box</u>:

☐ I have read the information sheet (version 1.0, dated 17/04/2020) and understand what is required of me.

☐ I have had the opportunity to ask any questions which have been answered fully.

☐ I understand that my data will be anonymised before any reports are produced for this project and that non-anonymised data will only be seen by the analysis team.

☐ I understand that I am participating in this study voluntarily and can withdraw at any point and without any explanation.

☐

I agree to my data being used for research purposes for this and any future projects. I agree to my data being used in any publications which may arise from this study, providing I cannot be identified.

☐ I agree to take part in this study.

Name of participant: Date:

Appendix 17–Prompt questions

The human impact of Covid-19 on RJAH staff – Week 1

Thank you so much for taking part in this project!

We would like you to produce a daily audio diary of your work experiences over the next 3 weeks. At the end of each day, we would like you to spend about five minutes reflecting on what happened: any events which occurred, how you responded to them, and how you feel. Each week we will provide you with a series of questions to guide your response and help prompt your thoughts. You are welcome to add any additional information that you think is relevant or important. There isn't a wrong answer and we'd like to know what you think.

Feel free to mention names and specific occurrences in your entry. The team will make sure that everything in your recording is anonymized and that no-one can identify you or anyone that you talk about. No-one outside of the research team will see the non-anonymised data, and we will treat everything that we receive as strictly confidential.

We recognise that this is a difficult time, so please do not feel under any pressure to produce an entry if you are too busy or tired! It is not a problem if you miss a day, please just include any comments about the missed day in the next entry that you do.

This can be recorded at any point after your working day using any equipment you feel comfortable with. Using your phone or computer is completely fine! When you have finished, please send the audio file to Caroline Stewart at: **caroline.stewart9@nhs.net**.

Prompts

Day 1:

How's it been so far?

Please use your time today to tell us about how you feel about the current situation and how it has affected you at work and at home. Up until this point: what has happened over the last few weeks, has your role at work changed, have you had any family commitments change? Please include anything that you think is significant about the effect that Covid-19 has had on your life and work environment: the highs and the lows and how you are coping with these changes/hopes for the future.

Day 2-5:

Daily catch up

We'd like you to spend five minutes or so reflecting on your day. The following questions are prompts, but feel free to include any extra information that you think is significant.

- What went well at work today and why?
  - Tell us about the most uplifting thing that has happened to you today and who or what was involved.
- What was the biggest dilemma or obstacle you faced at work today?
  - What happened, who or what was involved?

- How has today affected you, and how has it impacted on how you feel?
- What, if anything, from today will you take forward into tomorrow or the future?
    - Are there any changes you would make to your future practice or working conditions?

The human impact of Covid-19 on RJAH staff – Week 2

Thank you for sending your diaries in so far, they have been really interesting and insightful!

Please continue your daily diary as you did last week: tell us about the good things, any dilemmas or obstacles, and any feelings which you have during the working day. These daily entries are really useful for the work that we're doing and we're enjoying reading through them.

This week we also have some more specific prompts. You may want to answer these one at a time in your entries, answer them in one block, or refer to them in your diary across the week. There is no right way to approach this, do whatever is easiest for you.

- How has your life changed during the covid-19 crisis, both at home and at work?
    - Have you changed how you think about things, or the things you prioritise?
- Do you think that communication has changed?
    - Is this different in formal and informal settings?
    - How do you feel about this?
    - Has it impacted on your work?
- Have you found that you have changed the activities that you do outside of work?
    - Do you use any of these to de-stress or relax?
- Tell us about your work-life balance. Has this changed during the Covid-19 crisis?

As before please feel free to include anything else that you would like to tell us which you feel is important or not covered in these questions.

Like last week, this can be recorded at any point after your working day using any equipment you feel comfortable with – this includes writing your entry rather than recording it, if you find this easiest. When you have finished please send your entry file to Caroline Stewart at: **caroline.stewart9@nhs.net**.

The human impact of Covid-19 on RJAH staff – Week 3

Thank you for continuing to send your diaries in, they have been really useful so far and we're so grateful for the support that you have given us. We hope that you enjoyed reading the summary of our findings.

This final week is made up of more structured questions which explore topics and themes which have emerged from your diary entries in more detail. We have written one for each working day of the week but please feel free to answer them however you see fit. You are also welcome to continue to discuss your day and anything else that you think is important; we are still reading these entries and will include anything you send us in our analysis.

As before please feel free to include anything else that you would like to tell us which you feel is important or not covered in these questions. Like last week, this can be recorded at any point after your working day using any equipment you feel comfortable with – this includes writing your entry rather than recording it, if you find this easiest. When you have finished please send your entry file to Caroline Stewart at: caroline.stewart9@nhs.net.

Prompt 1

How do you feel about the immediate future and the wider reopening of the hospital services?

- Do you feel ready?
- Is your workplace ready? Is there clear communication about this?
- How will this affect your future role or work?

Prompt 2

A large number of people have experienced flexible working during the Covid crisis.

- How effective and equitable do you think that flexible-working has been across the hospital?
- How do you feel about your experience of flexible working so far?
- Do you see this continuing into the future? Could your role integrate greater flexibility?

Prompt 3

Communication during the pandemic has been rapid and has changed on a daily basis both at a societal and organisational level.

- How has communication affected you and your role at work?
- How confident are you in the leadership's methods and style of communication? What could be improved in the near future?

Prompt 4

The hospital's crisis management process has been developed and updated as new data and regulations came to light.

- How has this affected your ability to work?
- Have you received adequate support when needed?
- What are your views regarding the 2m self-distancing requirements and the need for wearing masks at work?

Prompt 5

What is your ideal picture of the immediate and medium term future?

- Which elements should be retained and incorporated into the future practices of the Trust?

- What are your most valuable personal learnings from coping with COVID (as an employee and as a member of the society?)
- What changes would you like to see in terms of communication, support and leadership within the Trust?

Appendix 18–Interview schedule

Interview prompts

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- How have you personally been affected by the Covid-19 pandemic? Can you give any specific examples of this?
- What have been the highlights and biggest dilemmas at work during the pandemic?
- Identify external factors which have affected you during the pandemic. Can you give examples of those which you have control over and those which do you have no say?
- How has the pandemic affected your work schedule and priorities? Give us some examples.
- How do you think that changes implemented during the lockdown have affected staff at RJAH?
    - What actions did you take, either personally or managerially, to facilitate these changes?
- Please give us an example of how you give formal or informal support to your colleagues.
- How has communication been handled across the Trust. Can you tell us how you typically receive Covid-19 updates, and whether you pass this information on to anyone?
- How do you envision the future?
    - What challenges do you think will affect you?
    - How prepared do you feel as a manager?
    - How prepared do you think the senior team is?

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- What is your current role and where do you sit in the organizational structure of the hospital?
    - How has the organizational structure of the hospital changed during the pandemic?

- What have been the highlights and biggest dilemmas at work during the pandemic?
- How has the pandemic affected your work schedule and priorities? Give us some examples.
- How would you define your leadership style?
- Identify external factors which have affected you during the pandemic. Can you give examples of those which you have control over and those which do you have no say?
- What are the crisis management procedures?
- To what extent do you feel that you can influence the Trust?
- To what extent do you feel that you can influence the System?
- How have you personally been affected by the Covid-19 pandemic? Can you give any specific examples of this?
- How do you think that changes implemented during the lockdown have affected staff at RJAH?
    - What actions did you take, either personally or managerially, to facilitate these changes?
- Please give us an example of how you give formal or informal support to your colleagues.
- How has communication been handled across the Trust. Can you tell us how you typically receive Covid-19 updates, and whether you pass this information on to anyone?
- How do you envision the future?

  - What challenges do you think will affect you?
  - How prepared do you feel as a manager?
  - How prepared do you think the senior team is?

Appendix 19– Researcher's Epistemology

Written 8th May 2020

This project has come about very quickly because of the pandemic, so it's been a whirlwind of a month. Mmm, so in terms of how i fit into the research and prior experiences/understanding, I know the hospital well and I know some of the people who work there, from earlier work experience and research. I'm writing this/doing this research from the middle of the pandemic/Covid-19 crisis, like lots of other people I felt at a loss and wanted to help people/the NHS so I was delighted to be able to take this project on, particularly given that I couldn't finish my earlier work. I'm also really excited to be able to work on research with my supervisors, and the director in the hospital, that's likely to support people and promote active change.

The NHS is presented as being really over stretched in the news, with staff experiencing high levels of stress and burnout. I know that the priority at the moment is treating the virus itself and looking at the physical symptoms but I think we'll be looking at the long term psychological and social effects of this for longer than people realise. I want to be able to share the voices of the people in the NHS who are working through this and hopefully let other people know what they're going through so that there can be better support for staff in the future. I guess that's kind of idealistic. I think I'll need to be careful that I don't jump to any conclusions from the diary entries we get. People are stressed from a lot of different angles at the moment and I wouldn't want to misinterpret what people say.

Hopefully it will be good and a useful experience for everyone though!